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Services For Youth With Autism Spectrum Disorders: A Study Of Educational Practices In Vermont

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SERVICES FOR YOUTH WITH AUTISM SPECTRUM DISORDERS: A STUDY OF EDUCATIONAL PRACTICES IN VERMONT

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Abstract

Autism Spectrum Disorder (ASD) continues to receive increasing degrees of national attention in parallel with increasing rates of occurrence (Baio, 2012; Centers for Disease Control and Prevention, 2014; Rice, 2009). The disorder's growing prevalence has been accompanied by controversies regarding the source of the disorder (Baker & Stokes, 2007), how it is diagnosed (Mandell et al., 2009; Wing, Gould, & Gillberg, 2011), and what treatments are applicable and effective (National Autism Center, 2009).

This qualitative research study utilizes survey data provided by Special Education Directors to explore the question of what types of treatments are implemented and supported by school districts for students with an ASD in Vermont. This exploration is provided in order to help develop an understanding of the degree to which research-based interventions are being supported by special education administrators throughout the state.

Data analysis consisted of a process of content analysis utilizing coding and cross-case analysis to identify themes such as: the gap between education, experience, literature, and practice; the role of data in intervention and treatment design; and the role that professional development, staffing, and available resources play in ASD treatment. By exploring available research regarding the clinical effectiveness of various treatments and by analyzing survey data, this study identifies areas of strength and challenge conveyed in participants' responses, and makes suggestions regarding potential areas of future growth.

Dedication

This study is dedicated to Phoenix and all children and adolescents experiencing an Autism Spectrum Disorder, in the hope that they may access appropriate services and supports.

Table of Contents

List of Tables

Chapter One: Introduction

Autism Spectrum Disorder (ASD) has become exponentially prevalent in recent years and has garnered increasing amounts of public attention. The American Psychiatric Association (2013) identifies ASD as "characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships" (p.31). Additionally, "the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association, 2013, p.31).

ASD is currently diagnosed on behavioral observations alone, as a biological assessment has yet to be developed. Previously, ASD did not exist as a formal diagnosis, and was comprised of three separate diagnoses, including Pervasive Developmental Disorder, Asperger's Disorder, and Autistic Disorder, accounting for a wide range of secondary features and diversity of behavior (American Psychiatric Association, 2000). With the publication of the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), these three previously separate diagnoses have been consolidated into Autism Spectrum Disorder, so as to improve the "sensitivity and specificity of the criteria for the diagnosis…and to identify more focused treatment targets for the specific impairments identified" (American Psychiatric Association, 2013, p.xlii). The authors of the DSM-V claim that "symptoms of these disorders represent a single continuum of mild to severe impairments in the two domains of social communication and restrictive

repetitive behaviors/interests rather than being distinct disorders" (American Psychiatric Association, 2013, p.xlii).

This study offers a review of the services and interventions that are provided for youth experiencing an ASD in Vermont, and in turn, examines the gaps that exist between interventions currently provided by public schools in Vermont and interventions supported by research.

Context

In 2006, The Centers for Disease Control and Prevention published data reporting that in the United States, 1 in 110 children born in 1998 experience an ASD (Rice, 2009). Two years later, data indicated that the rate of incidence across genders had increased to 1 in 88 (Baio, 2012). Recent data from the surveillance year 2010 indicates continued growth in this trend, with 1 in 68 children presenting with an ASD (Baio, 2014), roughly a 30% increase from 2008 data. (Centers for Disease Control and Prevention, 2014). More specifically, 1 in 42 boys and 1 in 189 girls were identified with an ASD (Centers for Disease Control and Prevention, 2014). To put these numbers into a more tangible, school-based context, a typical school district consisting of 10,000 students serves nearly 100 children with ASD (Lord & Bishop, 2010, p. 8). Estimates gathered using survey reports by parents of school-aged children suggest that during 2011-2012, 2% of children between 6-17 years of age experience an ASD; this is contrasted by 1.16% reported by the same measures in 2007 (Blumberg et al., 2013).

With increasing numbers of individuals experiencing an ASD, and a parallel increase in the cost of treatment and care placed upon their families and society at large, a

great deal of effort has been made to identify the cause of these disorders. The mystery surrounding the origins of ASD has led to instances whereby a purported source is identified as a causal element in the public sector, prior to its confirmation via scientific evidence. A notable example of this is the claim that the use of thimerosal, a mercury based preservative, causes ASD, although no significant scientific findings supporting such a claim (Baker & Stokes, 2007, p. 757).

While the causes behind the emergence of ASD remain hidden, there is no shortage of treatment methodologies. There exists a wide range of interventions, including those founded on research demonstrating efficacy, as well as those lacking clinical validation. In navigating these myriad services, Koegel and Koegel (1995) noted:

> No one individual or group of individuals has unlocked all of the complex variables involved in autism...a coordinated effort by all involved can greatly enhance the functioning level of the child with autism and concomitantly reduce the tremendous familial stress associated with having a child with a disability (p. ix–x).

With each student experiencing an ASD requiring differential treatment, the projected costs for schools can skyrocket. In my own experience, an evidence-based behavioral program that includes direct one-on-one intervention and consultation to support a school-aged child with an ASD can easily cost between $70,000 and $120,000 per year, per student. Programs that include treatment such as discrete trial learning, which may include thirty five hours a week of one-on-one behavior intervention in the child's home, range from $40,000 to $60,000 per year (Chasson, Harris, & Neely, 2007). These cost estimates do not include the cost of additional services such as occupational

therapy, physical therapy, special education services, and so forth.

Lord and Bishop (2010) argue that professionals carry responsibility for identifying treatments likely to produce measurable improvements (p.11). Despite this, in 2001 it was estimated that fewer than one out of ten children with ASD received appropriate early intervention (National Research Council, 2001), and while some states have improved in this area, others have deteriorated (Lord & Bishop, 2010, p. 11). The costs school districts incur in their education of students experiencing an ASD can quickly become a large portion of their budgets. The issue of funding is prevalent in many discussions around ASD services, just as funding is a core component of virtually any discussion regarding education. In the case of ASD services, however, it is possible that funding is often named largely because it is a salient and easy referent that can be discussed in lieu of the myriad nebulous factors also associated with ASD. In other words, it may be easier to debate funding than to solve the other complex clinical, medical, and educational problems pertaining to ASD.

Significance

Many scholars have observed a gap between those services supported by research and services available or applied within the public school context. The existence of extensive misinformation on the topic of effective treatment and services for youth with ASD results in false hope and red herrings for individuals experiencing the disorder, their families, and professionals alike (Dillenburger, 2011; Maurice, Mannion, Letso, & Perry, 2001). In Vermont, for example, the State of Vermont Agency of Human Services and the State of Vermont Department of Education (now known as the Agency of

Education) have noted that no single program or strategy can meet the needs of all students with ASD, and argue that services should be developed on an individual basis using comprehensive assessments as guidance (McFadden & Bruno, 2006, p.41). The unique needs of those experiencing an ASD present challenges for those who work to develop consistent policies, as individualization is a difficult concept to explain and implement in a reliable manner.

Research based, effective classroom practices are at times inconsistent with methods implemented in the classroom, a gap that is especially evident in regards to learners with ASD (Mayton, Menendez, Wheeler, and Zhang, 2010, p.539; Parsons et al., 2013). In some cases, choices are made in favor of strategies that are marketed well but lack evidence, out of a desire and hope to improve outcomes for children (Parsons et al., 2013, p.269; Goin-Kochel, Myers, & Mackintosh, 2007; Hess, Morrier, Heflin, & Ivey, 2008). Parents and professionals alike encounter an evidence base that is at times vague, controversial (Parsons et al., 2009), and lacks clear guidance from researchers about best practices (Simpson, McKee, Teeter, & Beytien, 2007). It is the intent of this study to provide professionals serving youth with an ASD with awareness of potential gaps between practice and research, as well as to provide those involved in public policy with awareness of this gap, so as to disseminate information that may be of use to those responsible for developing and implementing policy.

Background and Role of Researcher

In my professional work over the past decade, I have come to know and work with many children and families affected by ASD. Through provision of direct

support/therapeutic intervention, case management, family therapy, and treatment design, I have gained significant exposure to the challenges, successes, and factors involved in treatment and related aspects of care. My interest in this research is born of these professional experiences, notably as a result of my involvement as a mental health care clinician whose work is inherently connected to these children and families' experiences with their public schools, and whose work is indelibly tied to collaboration with public school systems.

Research Statement

Given the potential for discrepancy between the ideals of research-based treatment and the actual treatment implemented, I sought to explore the question of what types of treatments are implemented and supported by schools or school districts for students with an ASD in Vermont, in order to help develop an understanding of the degree to which research-based interventions are being supported by special education administrators throughout the state. Through the application of a survey consisting of open-ended questions developed through consultation with professionals in the field, I conducted an exploratory qualitative study that produced a review of common interventions, treatments, and related services implemented by public education providers in the state of Vermont, as well as their perspectives regarding the underlying reasons for applying certain treatments. The findings in this study pertain to services implemented within each district, as reported by the administrator of special education for each district. For the sake of clarification, the terms 'treatment' and 'intervention' refer to treatment design, (e.g., individualized programming including specific interventions, and specific

models of support, such as Applied Behavior Analysis, Social Stories™, etc). The term 'service' refers to specific interventions such as physical therapy, speech and language pathology support, etc.. This survey was completed by special education directors/directors of special services within each supervisory union in Vermont. The results of the survey, including the types of treatment typically provided in Vermont and the reasons providers are selecting such treatments, were then analyzed. This analysis determined the degree to which these treatments are supported by research, for the purpose of providing professionals and policy makers with awareness and information pertaining to the gap between practice and research.

Research Questions

This study seeks to describe what treatments are provided for youth experiencing ASD in public schools in Vermont, from the perspective of special education administrators who oversee service delivery and practices in their districts. In support of this primary question, the following research questions were addressed:

- What services/interventions are provided for children/adolescents with an ASD in school districts in Vermont?
- How are these services/interventions implemented for children/adolescents with an ASD within school districts in Vermont?
- Why are these services/interventions applied to students with an ASD in school districts in Vermont?

Chapter 2: Literature Review

In this chapter, I provide a review of the individualized nature of ASD treatments, services, and intervention, with specific attention given to applied behavior analysis, theory of mind, Social Stories™, complementary and alternative medicine, and the role of evidence based practices. I also examine the way treatment decisions are made, offering a review of the factors at play for children, their families, and school teams in the application and delivery of services. I engage in this review of treatment related literature to provide the reader with an understanding of the myriad of treatment modalities commonly applied in serving youth with an ASD, as well as to illustrate the complexity of the decision-making process and the issues common to service provision for youth with an ASD.

Following the review of issues pertaining to the treatment and delivery of services to individuals, I explore some of the major societal issues facing both those affected with an ASD and the public policy makers whose decisions impact them. I do this in order provide the reader with an understanding of the broader context in which ASD treatment and services operate. This section also discusses ongoing legal, fiscal, and policy related issues.

Nature of Autism Treatments

ASD is treated with a wide variety of methodologies. A review of digital sources, journal articles, and the broader World Wide Web reveals treatments ranging from the extensively studied to those lacking any formal evaluation or systematic research (e.g., claims to cure ASD via simple diet changes, curing the symptoms of ASD

through swimming with dolphins, and so forth). Levy and Hyman (2008) suggested that simple treatments such as diets, or those promising extraordinary outcomes, may be more readily accepted by parents because of their straightforward, scientific-sounding nature, in contrast to multidisciplinary approaches, which can often be confusing and complicated. In some cases, strategies that may hold benefit for individuals with an ASD are misunderstood as a cure, as opposed to an effort to improve quality of life or alleviate specific symptoms.

Regardless of what educators, parents, and/or mental health professionals believe to be efficacious, research has demonstrated that each individual case of ASD requires a collaborative effort between treatment providers and parents, with parents serving as integral, respected partners (McFadden & Bruno, 2006, p. 15). Volkmar, Paul, Klin, and Cohen (2005, p.1061) identified eight research-based approaches as central to working with families of children with ASD, including: providing families with access to professional literature, training parents in behavior management techniques, helping family members apply principles of learning to education management, helping family members to manage the parent-child relationship, training family members in cognitive techniques to modify emotional and behavioral responses, providing family members with their own therapeutic supports, assisting family members in gaining access to services, and assisting family members in advocating for the child's needs.

The following sections provide a brief overview of predominant treatments, services, and interventions for children with an ASD, beginning with evidence-based interventions and ending with Complementary and Alternative Medicine and its role in

ASD treatment.

Applied behavior analysis. ABA is unusual in the realm of identified treatments for ASD in that it is considered both a treatment in and of itself and concurrently serves as part of a multidisciplinary model. While ABA may be used as a primary intervention to address individual-specific goals, the same function may be applied to address goals across any area of the young person's life. For example, ABA may be utilized to treat specific behaviors, and it may also serve as an underlying treatment supporting access to other interventions as well. ABA is not a single-track treatment methodology, but rather is comprised of a variety of methods applied individually while incorporating supports from other programs and interventions. For example, ABA methods may include the use of the Picture Exchange Communication System (PECS), a behaviorally based intervention commonly used to support functional communication in pre or non-verbal children with or without an ASD. ABA fulfills the need for a high degree of differential treatment, while at the same time providing an umbrella under which treatments carry a high degree of cross-influence and intradependence, because it offers an empirical method for supporting and measuring an individual's progress towards specific, established goals. "There is little doubt that early intervention based on the principles and practices of ABA can produce large, comprehensive, lasting, and meaningful improvements in many important domains for a large proportion of children with autism" (Green, 1996, p. 38). In some cases, the improvements resulting from this treatment can result in students achieving levels of functioning typical for their age (Green, 1996, p. 38).

ABA is often cited as the treatment model with the strongest empirical evidence (Rosenwasser & Axelrod, 2001, p. 671) and has received an endorsement by a U.S. Surgeon General (U.S. Department of Health and Human Services, 1999). The early work by Lovaas (1987), which emerged from behavior analysis interventions beginning in the 1960's, demonstrated that with the appropriate treatment, children experiencing ASD could achieve gains that were previously thought to be impossible (Rosenwasser & Axelrod, 2001, p. 672). Rosenwasser and Axelrod (2001) showed that Lovaas' study provided direction for educators and researchers primarily through demonstrating the importance of language training as well as the fact that early, concentrated, and sustained intervention can help a student achieve functioning typical for their age. Perhaps most importantly, Rosenwasser and Axelrod (2001) identified that Lovaas' work showed that children with ASD could achieve the goal of inclusion within their mainstream school environments (p. 673).

At its most basic, ABA utilizes concepts from behavioral psychology to "support socially and educationally useful repertoires and decrease or reduce problem behaviors through the use of specific, carefully programmed environmental interventions" (Foxx, 2008, p. 825). A practitioner of ABA conducts descriptive and systematic behavioral assessments, including functional analyses, and provides behavior analytic interpretations of the results. ABA utilizes principles from behavioral psychology to support the general guidelines for effective interventions for children with an ASD which include: early intervention, intensive supports, a focus on parental training and support, a focus on social and communication domains, systematic treatment

addressing individual goals and objectives, and skill generalization (Foxx, 2008, p. 826). ABA methods often include the use of positive reinforcement, shaping, fading, prompting, and maintenance and generalization strategies (Foxx, 2008, p. 825). Many successful multidisciplinary approaches to treating individual cases of ASD include techniques drawn from ABA.

ABA is a scientific, evidence-based practice with efficacy for improving a range of skills across environments (Green, 1996, p. 31). Lovaas (1987) indicated that 47% of children receiving 40 hours a week of treatment via one-on-one delivery of ABA by trained therapists in their home, school, and community environments demonstrated average gains of 37 points in intellectual quotient and successfully completed a typical first grade class. This was contrasted with a control group receiving only 10 hours of behavioral treatment, along with additional non-behavioral methods, in which 42% of the group demonstrated average gains of six intelligence quotient points, and completion of an adapted first grade tailored for language delays and learning disabilities.

Significant variation in accreditation and licensure exists across the United States in regards to those purporting to practice ABA; within our own state, we may find many individuals with titles such as Behavior Specialist, or Behavior Consultant, without any requirement beyond a general bachelor's degree, and also may claim to implement ABA practices. In attempt to provide more clear distinction in this area, a national organization named The Behavior Analyst Certification Board (BACB) provides certification procedures for Board Certified Behavior Analysts (BCBA), Board Certified Assistant Behavior Analysts (BCaBA), and Registered Behavior Technicians (RBT),

while also carrying their own accreditation through the National Commission for Certifying Agencies (Behavior Analyst Certification Board, 2015). In Vermont, the implementation of Act 158, which relates to health insurance coverage of early childhood developmental disorders, including ASD, has set forth the requirement that ABA services be provided or supervised by a BCBA, or by licensed psychologists (Agency of Human Services, 2014). The increasing degrees of formal recognition of professionals with the training and certification for practicing ABA has helped create more definitive expectations for the implementation of ABA, for example, through providing regulations around professionals who claim to implement ABA practice, as well as established practice guidelines (Behavior Analyst Certification Board, 2014).

However, criticism of ABA is far from nonexistent. Some criticism of ABA comes from individuals who promote interventions lacking research or evidence suggesting validity, and even in some cases from proponents of interventions that are described as pseudoscience (Foxx, 2008, p. 823). Behavioral treatments such as ABA also face criticism from a functional perspective, as some critics claim that ABA makes children "robot-like," and only able to act "normal" in a rote fashion (Green, 1996, p. 32). These criticisms may not take into account the nature of the intervention: to actively engage the student in their physical and social environments. In the case of the Lovaas (1987) study, after receiving treatment, students demonstrated flexible behaviors that were judged as normal behavior by teachers and examiners who did not have prior knowledge of their diagnosis (Green, 1996, p. 32). Additionally, resistance has been observed from educational and government agencies who resist the expense associated

with individualized programs (Foxx, 2008, p. 823) that include ABA.

Theory of mind. The term theory of mind (ToM) originated in Premack and Woodruff's (1978) article exploring the cognition of chimpanzees, and refers to the "(quite unconscious) ability to attribute mental states, and to use these invisible postulates to explain behavior in everyday life" (Frith, Happe, & Siddons, 1994, p. 109). In the context of ASD, this translates to a deficit in one's ability to reciprocate in typical social interactions. Children with ASD often do not understand a speaker's intended meaning or the contrast between real and imaginary events, which is dependent upon one's innate mechanism to appreciate others' thoughts and feelings (Frith et al., 1994). Many scholars hypothesize that people experiencing ASD lack a theory of mind, that they experience impairment in their ability to understand their own and other's mental states (Frith et al., 1994).

Early work on the topic of ToM by Baron-Cohen, Leslie, and Frith (1985) explored the discrepancy between the social functioning of individuals with an ASD versus those with other cognitive impairments, such as Down Syndrome, and gave examples whereby intelligence quotient did not present itself as a correlating variable with social functioning. In consideration of cognitive mechanisms independent of intelligence quotient, Baron-Cohen and colleagues explored a model of metarepresentational development that presents "a mechanism which underlies a crucial aspect of social skills, namely being able to conceive of mental states, that is, knowing that other people know, want, feel, or believe things" (Baron-Cohen et al., 1985, p.38). Although ToM does not give a full account of ASD, it contributes to our understanding of

impairments in play, social interaction, and verbal and non-verbal communication (Frith & Happe, 1994).

Rather than offering specific intervention or treatment methodology, ToM presents a conceptual framework that informs other specific interventions designed to increase an individual with ASD's understanding of the states of others (Ozonoff & Miller, 1995; Silver & Oakes, 2001). Ozonoff and Miller examined the relationships of ToM to social skills training using systematic instruction in ToM principles, and reported substantial improvement on false belief tasks in which a person has to demonstrate understanding of another's mental representation of a situation as being different than their own. The authors noted that participants with an ASD may have learned to solve false-belief tasks but not necessarily achieved 'theory of mind.' Regardless of this distinction, this study demonstrated that false-belief tasks were teachable. As an extension of the false-belief component, Hutchins and Prelock (2008) presented that false-beliefs are not all encompassing when considering ToM. It was noted that false belief "represents an important component in the development of ToM." However, ToM goes beyond a focus on false-belief tasks, as it focuses on language competencies as a part of social-cognitive development (Hutchins & Prelock, 2008).

The most recent standards-based report by the National Autism Center (2009) lists ToM training as an intervention with an emerging evidence base, such that "one or more studies suggest the intervention may produce favorable outcomes" (p.57). The measurability of ToM interventions is likely a source of strength for the model, as found in the development of psychometric evaluation such as the Perceptions of Children's

Theory of Mind Measure (PCToMM-E), which presents a valuable parent-report measure of a child's theory of mind (Hutchins, Bonazinga, Prelock, & Taylor, 2008).

Social stories. Gray (1995) developed Social Stories™ in an effort to support individuals with ASD in their understanding and ability to implement social protocols. Social Stories™ are individualized stories with visual and textual content that "describe social situations in terms of relevant social cues and appropriate social responses" (Swaggart et al., 1995). Social Stories™ are typically comprised of two to five sentences that include identifying information about the setting, subjects, and actions taking place, as well as providing statements telling the reader the appropriate behavioral response that the character in the story should produce. Additionally, the feelings and reactions of others in the story are described, as well as analogies of similar actions and responses (Swaggart et al., 1995, p. 1-2). The design of Social Stories™ draws from elements of other interventions common within the treatment and education of children with an ASD, such as priming and visual supports (Lorimer, Simpson, Smith Myles, & Ganz, 2002, p.53).

Through the use of Social Stories™, children with an ASD are provided with specific pictorial and textual cuing for targeted social behaviors, including the use of video feedback in some cases (Thiemann & Goldstein, 2001). Social Stories™ are also instrumental in interventions targeting ToM competence, as they explicitly state the content of other people's thoughts (Hutchins & Prelock, 2006). The outcomes associated with the use of Social Stories™ may be influenced by multiple factors, such as a student's receptive and expressive language skills, their age, cognitive ability, and the

severity of their presenting diagnosis (Hutchins & Prelock, 2006).

Some discrepancy in research support of Social Stories™ exists, with some researchers reporting limited empirical foundation for the intervention (Sansosti, Powell-Smith, & Kincaid, 2004). In contrast, story-based intervention packages, which includes Social Stories™, is listed as one of the National Autism Center's (2009) eleven established interventions for ASD: demonstrating a research base for increasing interpersonal and self-regulation skills among 6-14 year olds with ASD. Preliminary evidence also suggests that Social Stories™ "can achieve clinically meaningful changes across a range of real-life contexts with a child with ASD," potentially supporting an individual's "access to the processes believed to operate in the typical development of social understanding" (Hutchins & Prelock, 2008, p. 357). This area of research holds particular interest in regards to methods to teach ToM, providing a means by which children with an ASD may "engage in shared meaning making and enable them to reason through social phenomena during episodes of language-mediated joint attention" (Hutchins & Prelock, 2008, p. 357).

Complementary alternative medicine. Complementary Alternative Medicine (CAM) is defined as "a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine (Akins, Angkustsiri, & Hansen, 2010, p.307). The application of CAM in the treatment of children with ASD is reportedly amongst the highest of any population, with use between 52% and 95%" (Akins et al., 2010, p.308). Alternative medical systems "build upon complete systems of theory and practice," and include mind-body interventions such as

meditation, prayer, art, music, and dance, which attempt to "enhance the mind's capacity to affect bodily function and symptoms;" biologically based therapies using naturally occurring substances such as herbs, foods, and vitamins; manipulative and body based methods that are based on the manipulation and/or movement of parts of the body such as chiropractic or osteopathic manipulation, or massage; and energy therapies involving "the use of energy fields" (Hanson et al., 2006, p. 629).

Apart from the primary influences of ASD on an individual's functioning, many children with ASD have other medical challenges that lie outside the scope of mainstream treatments. Families often turn to CAM to address these medical challenges, such as sleep disorders, gastrointestinal issues, sensory integration issues, and so forth. Because the definitions of CAM often include concepts that relate to issues outside of recognized science, concerns are raised. CAM is defined as "a broad domain of healing resources that encompasses all health systems modalities and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system" (Panel of Definition and Description, 1995), or as "strategies that have not met the standards of clinical effectiveness, either through randomized controlled trials or through the consensus of the biomedical community" (American Academy of Pediatrics, 2001). These definitions and construction of CAM present a significant challenge in that issues of belief and politics become involved in issues pertaining to treatment efficacy. For example, in the case of gluten and casein free diets used to support an individual with an ASD who is also experiencing gastrointestinal challenges, the National Autism Center's National Standards Report (2009) identifies that "the quality, quantity and

consistency of research findings have generally been poor or do not apply to individuals with ASD" (p.70); in spite of this lack of evidence, some doctors and parents choose to implement these diets.

The source of information available about CAM to families is considered questionable by some, as Akins and colleagues (2010) identified the two most likely sources of this information to be a friend or family member, or the internet (p.308). The internet provides an increased exposure to the effects of marketing, selected testimonials, and unproven claims (Akins et al., 2010, p.308). Claims of treatment efficacy with limited supporting evidence are not limited to the internet. For example, Horvath and colleagues' (1998) reported significant behavioral improvement in social and language skills among children with ASD after receiving secretin. Their findings were cited widely amongst public outlets such as newspapers, television, and the internet, and became an influence for many clinicians to begin prescribing secretin for ASD despite the report being a clinical observation of only three children (Sturmey, 2005, p.88). Sturmey's (2005) review of fifteen double-blind, placebo controlled trials later found that there was no evidence supporting the purported correlation between secretin and behavioral change (p. 88).

The presence of personal belief in these therapies, coupled with a lack of sufficient evidence-base for these CAM therapies, can lead to a schism between families and their conventional care providers, which may play a hand in the report that a majority of parents do not inform their doctor that their child is using CAM (Sturmey, 2005, p. 309). This challenge of non-disclosure may also be tied to the lack of conversation

initiated by physicians, as CAM is rarely discussed with parents and families (Golnik & Ireland, 2009), as physicians may omit such information because of the lack of clinical trials demonstrating efficacy, a lack of available safety information, or a lack of physician education (p.997).

The often unspoken topic of CAM is identified as a barrier to care for children with ASD and also as an area of tension between a family and their physician should the physician discourage the use of CAM (Golnik & Ireland, 2009, p.1001). The suggestion for physicians to familiarize themselves with CAM and to take it upon themselves to openly engage families in conversation about this topic is provided as a means to help redirect the stream of information available to families, as well as to provide families with a means of becoming educated about not only available treatments, but also about the hierarchy of evidence and basic research practices (Akins, et al., 2010; Golnik & Ireland, 2009). Harrington, Rosen, Garnecho, and Patrick (2006) identified, "as in culturally competent models of care, health care professionals need to consider the viewpoint and perspective of this growing population of children and parents by familiarizing themselves with their shared commonalities" (p.157).

Treatment: Decisions and Delivery

School districts often face a significant challenge in their attempts to implement the recommendations emerging from research. The educational goals for children with ASD are largely the same for other students, in that students are primarily working towards achieving personal independence and social responsibility (Stichter et al., 2006). Also similar for all students is the challenge that school districts face, in their efforts to

integrate the recommendations provided by research into their everyday practice (Stichter et al., 2006). Addressing this challenge often requires expertise in ASD interventions in addition to maintaining a "strong interdisciplinary knowledge-base in educationally relevant practices" (Stitcher et al., 2006, p.20).

One of the challenges associated with determining the efficacy of particular treatments is that outcomes associated with research using self-reporting by parents and professionals may be affected by the role that belief and hope play in assessment of treatment efficacy. Parents and professionals may often report that a treatment was successful, even though it was not, because they wish it to be (Smith, 1996, p.45). Some families experience psychological stress, as "the pressure on families to make the 'right' intervention choices for their children is not only a legitimate concern but one with great consequences" (Conroy, 2010, p.99). Similarly, professionals experience pressure as well, as they grapple with the question of how to present the relatively limited and emerging knowledge that exists about identification and intervention to families in a way that is meaningful and helpful (Conroy, 2010, p.100). In some cases, parents of children with an ASD diagnosis were observed to fall into one of two camps: those who requested that the district exhibit more leadership regarding the interventions applicable for their child, including a clear definition of the best approach, contrasted by those who identified specific approaches as being the only hope for their child. Parents in the second group were observed to be requesting that the school implement a specific approach that was at times contrary to the recommendations of service providers (Stitcher et al., 2006, p.19).

Further complicating the task of bringing effective, meaningful practices into the

family systems supporting children diagnosed with ASD is the fact that professionals must often play a major role in supporting families. There is much yet to be understood regarding how the dynamics of a family system can interact with intervention processes and ultimately influence outcomes (Webster, Feiler, Webster, & Lovell, 2004). Behavioral interventions are largely based on the premise that behavior can be modified through contextual manipulation: a premise that in research settings accounts for a high degree of observable factors, and yet, the home and school environments often cannot account for the myriad factors at play. Some authors have argued that intensive intervention processes based on experimental research design, such as ABA, should be supplemented with qualitative data detailing the family system's social functioning. This would provide a broader perspective on the larger system that invariably intervenes in the child's functioning, whether as a result of the family's social processes, or by way of planned intervention (Webster et al., 2004).

Webster and colleagues (2004) identified a common problem in the assessment of strategies for supporting children with an ASD diagnosis: when researchers assume that any strategy resulting in positive outcomes must be beneficial, the negative consequences of intensive treatments may be overlooked (p. 27). The impact of intensive treatment programs, which are often based out of the child's home, can place an exceptional amount of stress upon the family in terms of both time and money. Perhaps more importantly, they can have a negative impact on the family system. Webster and colleagues claim that assessments of interventions that focused solely on the child's outcome, without examining the impact of the interventions upon the family, are unlikely

to assist in the development of effective practices (p. 28).

Evidence-based practice. The notion that science should guide practice in special education is generally agreed upon; however, as many researchers have noted, implementing the details of this arrangement is quite complicated (Odom et al., 2005). Policies such as the No Child Left Behind Act as well as the Individuals with Disabilities Education Act explicitly state that teachers are required to use scientifically proven practices as well as to support their practices with an understanding of research (Linn, Baker, & Betebenner, 2002; Odom et al., 2005). These policies were enacted in part due to the belief that utilizing evidence-based practices results in better outcomes for students with special education services.

Definition and role. A key consideration in determining treatment efficacy is the degree to which practitioners and families understand and use evidence-based practices (EBP); however, a review of the literature also indicates that EBP is understood differently by various professional organizations and disciplines. In the medical field, a generalizable understanding of the definition of Evidence Based Practice (EBP) is present: it represents the intention of minimizing the "gap between research and practice with the end goal being directed toward the use of scientific evidence as the method of choice for physicians in the diagnosis and treatment of illness" (Mayton, et al., 2010, p.539). This overarching philosophy of joining research with practice is universal with EBP; however, different understandings of how EBP is utilized exist across the field of special education and ASD services.

One example of the interpretation and understanding of EBP in an educational

context is found in literature from the Council for Exceptional Children (CEC). The CEC states that EBPs represent efforts to require research support for the practices that are implemented (Cook & Cook, 2011). To delve deeper into the issue, under the CEC's approach "EBPs are not self-implementing mechanisms that will be embraced and utilized automatically as they are identified" (Cook & Cook, 2011, p. 2). The CEC's definition of EBP focuses on aspects pertaining to what constitutes an EBP: research design, quality of research studies, quantity of research studies, and magnitude of effect (Cook & Cook, 2011, p.4-5). Additionally, it was noted that EBPs are not to be considered a panacea, due to a lack of guarantee that they will work for everyone, the fact that they may be difficult to implement on a broad scale, and that EBP is one of many considerations at play when it comes to instructional decision-making (Cook & Cook, 2011).

Another example of how EBP is understood may be found in the American Speech-Language-Hearing Association's (2013) representation: that EBP seeks the integration of: (a) clinical expertise/expert opinion, (b) external scientific evidence, and (c) client/patient/caregiver perspectives to provide high-quality services reflecting the interests, values, needs, and choices of the individuals served. In this definition, the American Speech-Language-Hearing Association provides a viewpoint that is often lost amongst the research literature on EBP:

> Because EBP is client/patient/family centered, a clinician's task is to interpret best current evidence from systematic research in relation to an individual client/patient, including that individual's preferences, environment, culture, and

values regarding health and well-being. Ultimately, the goal of EBP is providing optimal clinical service to that client/patient on an individual basis (para. 4).

This conceptualization of EBP as a culmination of research, specific individual needs and perspective, and clinical expertise and opinion stands in contrast to the misperceptions or misunderstandings that often lead to criticism of EBP. For some, EBP may be perceived as being limited in scope, or limited to only applying research supported practices without taking into consideration the context of application. Questions regarding the interpretation of evidence may arise, as well as opinions that EBP leads to a "straitjacket or a cookbook approach in which both clinician judgment and patient values and circumstances are ignored" (Straus, Haynes, Glasziou, Dickersin, & Guyatt, 2007, p.2). One perspective holds that the term EBP may be used in two different ways: as an approach to decision-making, or, in reference to specific practices (Cook & Cook, 2011). This is a perspective that helps to shape an understanding of all that the term EBP can encompass, rather than the cookbook approach it is often.

Significance. As it pertains to special education, "EBPs are important for students with disabilities because they represent a tool for identifying the instructional practices most likely to improve school outcomes" (Cook, Shepherd, Cothren Cook, & Cook, 2012). Cook and colleagues claim that "most special education stakeholders share a general notion that evidence based practice refers to instruction that is supported in some manner by research," however, use of this term is often indiscriminate and inappropriate, with many educators and parents lacking an understanding of exactly what

EBPs are, and how to identify them (p.22). Much like general education, special education has encountered a gap between research and practice (Mayton et al., 2010, p.539). This gap between what research literature has suggested as the criteria for being considered an evidence-based practice, and what is implemented by special educators, poses a recognizable threat to the well-being of students with an ASD and their families (Mayton et al., 2010, p.540).

Amongst interventions commonly accepted as being EBP, few of these interventions were found to meet the National Professional Development Center's definition of EBP for individuals with an ASD diagnosis (Mayton et al., 2010, p.548). This discrepancy between what is accepted as EBP, and what actually qualifies as EBP was thought to be a result of several shortcomings, including inadequate geographic distribution of research, low number of research participants, and insufficient effect sizes (Mayton et al., 2010, p.549). These findings were interpreted as a call-to-task for researchers to improve several aspects of research, primarily around the level of scrutiny and quality of their work (Mayton et al., 2010, p.550), as it appears that this gap between EBP and reported research may be a function of shoddy research practices, rather than insignificant findings.

In order to determine whether or not a practice qualifies as an EBP, researchers participate in systematic reviews of the literature regarding instructional practices, examining the design, quality of research, magnitude of effect, and quantity of supporting research for each chosen study (Cook et al., 2012, p. 24). Multiple methods exist for determining whether or not a practice qualifies as an EBP, and to what degree a practice

qualifies as an EBP. Given the individualized nature of treatment planning and programming, single-subject research provides an area of strength as it has proven itself to be relevant for defining educational practices for each individual learner (Horner et al., 2005, p.165). Single-subject research offers a design that provides experimental control as well as a data-driven model of treatment: aspects of intervention which are immensely important in tracking the improvement of target behaviors. Single-subject research design is supported by over 45 professional journals as a means of providing systematic and detailed analysis of an individual's treatment (Horner et al., 2005, p.166). The single-subject research model is in fact a critical component of ABA treatment design, as both models employ one or more dependent variables that are defined and measured, with dependent variables representing the behaviors providers seek to change, improve, or extinguish, and the independent variables representing the element being studied (Horner et al., 2005, p.167). The implementation of single-subject research design via treatment/education methodology provides both researchers and treatment teams with a means of assessing the efficacy of any given intervention, as well as the treatment model as a whole.

While implementation and education involving EBPs may seem straightforward at first glance, Kamhi (2011) remind us of a common pitfall in the application of scientific methodology: that merely seeking evidence to support one's belief is contrary to the structure of EBP (p. 59) because this may result in ignoring contradictory evidence, and lend susceptibility to confirmation bias. Kamhi has argued that practitioners' concern for their patients and their skepticism about trying innovative approaches should

be supported by the principles of EBP, leading towards optimized clinical practices (p.61-62).

Understanding and implementation. A common misunderstanding of what EBP represents can be characterized as "the static implementation of a scientifically proven intervention rather than an individualized clinical process," with prominent internet sources such as Wikipedia also identifying EBP in such a light (Kamhi, 2011, p.62). Rather than serving as a cookbook, or as a prescriptive application of a practice supported by research, EBP "represents a framework for people to find, understand, and apply the current best scientific evidence, bearing values and preferences in mind, when making decisions concerning their health or when helping others to do so" (Straus et al., 2007, p.3). Criticism of this understanding of EBP's role in supporting clinical decision-making is found in work by authors such as Apel (2011), who has offered the opinion that "it is the educators of future researchers and clinicians, not EBP…who must be the mechanism for helping future clinicians develop scientific clinical decision-making skills" (p.65). Apel shared the belief that "we should strive to have research scientists who understand clinical practices and clinical questions, and clinical *scientists* who are open to discussing and exploring their uncertainties and certainties in research venues. These types of individuals may readily build the bridge and break down the preconceived barriers between research and practice" (p.67).

The lack of a single, clear definition of EBP, and the presence of several interpretations of EBP across professionals, fields, and contexts, likely contributes to the challenges associated with it. Any given definition of EBP may be accurate, and an

individual may grasp a strong understanding of one of many definitions; however, without a comprehensive understanding of the breadth of definitions and interpretations, that individual may only perceive one aspect of EBP.

In order for clinicians to effectively utilize EBP within the scope of their practice, rational thinking can provide a safeguard against unbalanced decisions (Finn, 2011, p.69). Critical thinking is an important component to the use of EBP, and that through engaging with EBP, clinicians and clients may be protected through the use of critical thought and consideration, an area of importance in the training of practitioners (Finn, 2011, p.71).

Outcomes. The outcomes of the implementation of EBP are twofold. First, it enables professionals to steer away from clinically unacceptable treatments in spite of endorsement by others (Justice & Fey, 2004). Secondly, it permits professionals to use coherent criteria to select clinically acceptable treatments (Justice & Fey, 2004). While these identifiers may appear to present cut and dry answers to issues pertaining to practice, as we read earlier in this section, EBP "does not place a singular focus on the use of evidence and research when making clinical decisions; rather, it emphasizes the need to consult the best available research to ensure clinical objectivity and currency" (Justice & Fey, 2004, p. 4).

EBP is a concept that creates significant opportunities for parental involvement, as special educators can provide parents with an understanding of the role that EBP plays in their child's education. Educators have several opportunities to collaborate with parents, such as team meetings, information and resource dissemination regarding EBP,

and development of fact sheets (Cook et al., 2012, p.27). Although parents may feel overwhelmed by the amount of information available to them, and/or that examination of EBP may be a responsibility of the educator(s), EBP presents as an effective means by which teachers can encourage parental involvement through utilizing their own experiences and understanding (Cook et al., 2012, p.27). The role of drawing from research as well as contextual variables and conditions in clinical practice is important across settings, and is perhaps the most salient in work involving home based services, an area I will discuss further in the following section.

Home based services. The role and capacity that a family system's social processes play in influencing intervention, as well as a clinician's ability to influence a family's social system, are immense. Research has demonstrated that parents of children with an ASD diagnosis report higher amounts of stress than parents of children with other developmental disabilities (Hastings & Johnson, 2001). Often these families encounter significant difficulty in accessing appropriate information, advice, and help from support services (Redmond & Richardson, 2003; Shearn & Todd, 2000).

The stress experienced by families with a child with an ASD is significant, with many variables increasing their day-to-day demands and strain. Often, the social lives of parents and families with a child experiencing an ASD are impacted by their ability to sustain friendships outside the family, feelings of isolation and ostracization, and negative effects on their relationships with other children in the family (Webster et al., 2004). Home based behavioral treatments provide an example of an ASD service that may be experienced differently across families. For some, home-based services may be

perceived as increasing the stress experienced by a family due to factors such as time commitments, financial demands, and opening one's home to numerous professionals. Hastings and Johnson (2001), however, found that despite these otherwise stressful factors, home based behavioral treatments did not appear to result in additional adverse effect for the parents. In this example, it is perceived that the added stress brought on by these interventions may be mitigated by the practice's influence on the parents' beliefs regarding the treatment (Cattell-Gordon & Cattell-Gordon, 1998; Hastings & Johnson, 2001).

Similarly, Grindle, Kovshoff, Hastings, and Remington's (2009) study of the parental experiences of home-based intervention with an ABA model reported increases in language and communication skills, social skills, and play skills. The authors noted that parents reported receiving additional support in the home around effective behavior management, and a widening of social networks through contacts made within their local community of parents facing similar challenges (Grindle et al., 2009, p.45-46).

Summary

The preceding review of literature pertaining to various treatment modalities applied for individuals with ASD is by no means comprehensive or complete. There is such a wealth of information available regarding treatments for ASD that a comprehensive literature review would unwieldy for the purpose of this document. The intent of this review is to provide the reader with an understanding of the context that exists within the world of ASD, that even among the modalities carrying the greatest degree of research base, conflict and disagreement exists; and among these methods with

the greatest dearth of evidence-base, favorable information is still widely disseminated.

In reviewing the aforementioned information pertaining to ABA, ToM, Social Stories™, and CAM, I provided the reader with a brief review of salient points of discussion within the current dialogue regarding ASD treatment. Likewise, in discussing issues pertaining to the decision-making process and delivery of services, I offered a review of EBP and the experience of a family with a child experiencing an ASD in effort to provide a summary of issues central to the topic of ASD service delivery.

The following sections will continue to provide contextual understanding of the world of ASD, in examining the areas of public policy, legal involvement, and cost of services.

Public Policy and Legal Implications

The exponential increase in the incidence of ASD during the past few decades has presented challenges not only to individuals experiencing the disorder and the people in their immediate networks, but also to those responsible for developing public policy aimed at meeting the wide range of needs expressed by those with ASD. In the previous section, I discussed factors that influence the decision-making processes that take place within school environments, for example, the student-by-student decisions made by IEP team. Here, I discuss public policy as a broader decision-making process that takes into account the aggregate of treatment decisions within a district; for example, determining how an educational system is able to address issues of management and treatment provision across the breadth of students diagnosed with an ASD within their district, county, region, etc.

We could conceptualize the decisions discussed in previous sections of this document as the micro-decisions that drive and determine the course of treatment. Public policy would then exist as the macro-decisions, the overarching structure that enables or disables professionals in their efforts to implement specific treatments, determines who is able to access treatment in their educational context, and how their experience is affected by larger political and economic conditions. The combination of a continued absence of an identified causal influence, the political and professional battles over the efficacy of any given treatment, and the social context, all appear to be calling for "increasing reliance on community and civil rights based policy responses to disability" (Baker, 2004, p.2). These elements all create a sizeable task for any individual or group seeking to develop policy and funding mechanisms seeking to help the breadth of the population affected by this disorder (Baker, 2004).

Diagnosis and policy. Public policy applicable to people with a disability is often shaped around the premise of a diagnosis. For example, an individual who utilizes a common treatment for mobility challenges is supported by public policy that mandates that buildings be accessible by wheelchair. By their very nature, ASD presents equivocal needs on a case-by-case basis, more often than not, with a changing nature and level of services over the course of a lifespan for each individual case. Baker (2004) wrote:

> Neither the exact needs nor the expected prognosis can be easily estimated on a case-by-case basis given diagnosis. By the same token, since establishing accurate prognosis for individual children is nearly impossible and the most effective treatment highly debated (presumably because the treatments have not well

> understood differential effects on different individuals), public policy that provides services on the basis of individual demands or rights can be equally and uniquely difficult in managing the social challenges associated with autism (p.3).

While each case presents its own specific treatment needs, there are common elements amongst many, if not all, cases of ASD that appear as generally agreed upon elements of effective practice. Early intervention, tailored treatments to the needs of specific children and their families, data driven teaching methods, specialized curriculums, maximizing intensity of child engagement, and fostering family involvement have all been found across expert opinions, in spite of differences in philosophy (Hurth, Shaw, Izeman, Whaley, & Rogers, 1999).

The diagnostic process and criteria for establishing a diagnosis of ASD underwent significant changes with the publication of the 5th revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), as this revision included a consolidation of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder into a single diagnosis of Autism Spectrum Disorder (American Psychiatric Association, 2013, p. xlii). Concern amongst the professional community was voiced prior to the publication of the DSM-V regarding a lack of attention to issues such as social imagination, diagnosis in infancy and adulthood, potential gender bias in diagnosis (Wing, Gould, & Gillberg, 2011, p. 768), as well as potential racial bias in diagnosis (Mandell et al., 2009). On a related note, concern is often voiced regarding the increase in prevalence rates as being a reflection of the widening of diagnostic criteria, rather than a reflection of actual increase in incidence. Researchers such as Wing (1981) argued that

this widening of diagnostic criteria is process that began with the early work of Hans Asperger, who identified patterns of behavior now known as Asperger's syndrome over seventy years ago.

The diagnostic process and criteria for establishing an ASD diagnosis is important because a narrowing of criteria could potentially limit or prevent access to services, a threat that has been perceived and responded to by individuals with ASD, families, and practitioners within the ASD community (The Global and Regional Asperger Syndrome Partnership, 2013; Garcia Winner, 2011). However, the American Psychiatric Association argued in their description of the change of classification and diagnosis that this consolidation was in part an effort to "improve the sensitivity and specificity of the criteria for the diagnosis" (American Psychiatric Association, 2013, p.xlii). While these concerns persist, professionals within the field, including some directly involved with the writing of the DSM-V, have produced documents assuring the public that no one would lose their diagnosis due to a change in criteria (Dawson, 2012). Official communications have asserted that field trials of the new diagnostic criteria suggest an increase in the reliability of diagnosis, and that "of the small number of individuals excluded, most received the new diagnosis of 'social communication disorder'" (Dawson, 2012, para. 4).

Educational requirements. The Individuals with Disabilities Education Act (IDEA) was originally passed by the U.S. Congress in 1975, establishing the entitlement of a free appropriate public education (FAPE) for all children with disabilities (Yell, Shriner, & Katsiyannis, 2006). The IDEA has been amended several times since its

passage, with changes to the act notable for the context of this study occurring in 1990 with the addition of ASD as a distinct disability category (Yell et al., 2006). Also, in 1997 the act was amended to respond to the call to include students with disabilities in general education classrooms per the least restrictive environment provision (Simpson, De Boer-Ott, & Smith-Myles, 2003). In 2004, the act was also amended during a re-approval process that reflected the influence of the No Child Left Behind (NCLB) Act of 2001 (Yell et al., 2006).

In discussing the challenges associated with facilitating the inclusion of students experiencing an ASD in general education classrooms, Simpson and colleagues (2003) reviewed the individuated planning necessary for their success, that challenges common to students experiencing an ASD would likely be exacerbated when they are educated in general education settings, and that including learners with ASD in typical classroom settings requires additional planning and consideration (p.116-117). The requirement to provide students with a FAPE in the least restrictive environment presents a challenge to educators seeking to support and educate students experiencing an ASD. The reauthorization of IDEA in 1997 provided that students are "entitled to educational services in maximally normalized settings that offer the greatest opportunities for contact with typical peers" (Simpson et al., 2003, p. 117), a mandate which is complicated by the evidence-base that students experiencing an ASD require individualized programming and support, although the individualized nature of ASD programming does not exclude that support from occurring within a classroom environment.

The reauthorization and changes to the IDEA through the Individuals with

Disabilities Education Improvement Act (IDEIA) of 2004 reflected significant influences preceded by the NCLB act of 2001, including the requirement that schools implement evidence-based practices, continuing the role that the federal government has in education to have a significant effect on students with disabilities (Yell et al., 2006, p. 2). The prospect of a profound effect for students with disabilities was based on a number of substantive changes, including the following requirements: relevant assessments, meaningful programs including measurable annual goals and appropriate special education based on peer-reviewed literature, regular monitoring and reporting on the progress of students in special education programs, and the adjustment of instruction when a student's progress is not sufficient to meet goals (Yell, Drasgow, & Lowery, 2005). The provision of appropriate special education based on peer-reviewed literature is important in the context of special education, including ASD, as this requires an individualized education program (IEP) team to develop a special education program based on reliable evidence of efficacy, and extends further in that professional development and funding be used in practices supported by research (Yell et al., 2006, p.11). These provisions may appear at first glance to be a matter of common sense, or perhaps a non-issue amongst professional educators, however, they address significant concerns and issues that do arise within some districts. The requirement that IEP services follow evidence-based practices and promote the inclusion of individuals experiencing an ASD requires that teachers stay up to date with research pertaining to academic and behavioral interventions (Yell et al., 2006, p.11). The requirement that teachers be able to support their practices with an understanding of the supporting research also creates

the potential for due process and litigation, as this proficiency with the evidence base behind their work is now a legal requirement (Yell et al., 2006, p.11).

IEP team meetings and decisions. The IEP process provides an opportunity to support collaboration between educators and parents (Fish, 2008, p.8). As a part of the IEP meeting, IDEA requires that a school district's personnel ensure meaningful parental involvement or active participation in the IEP process (Drasgow, Yell, & Robinson, 2001; Salas, 2004) and confirm parents' understanding of procedural rights and proceedings (Kalyanpur, Harry, & Skrtic, 2000; Yell, Katsiyannis, Drasgow, & Herbst, 2003).

One of the largest and most controversial components of the decision making process that an IEP team undertakes is that of placement. Determining how to provide a student with a FAPE in the least restrictive environment is one of the most frequently litigated and contested requirements under the IDEA (Yell, et al., 2003, p. 184). Given the lack of a substantive definition of FAPE, ambiguity has led to varying definitions of what constitutes a FAPE, per the individual needs of a student with disabilities (Womack, 2002, p.2). Through an IEP team's process of determining what special education and related services apply to a child's individual needs, "an increasing amount of litigation has centered around parents [of children with an ASD] who wish to include the Lovaas method (ABA) in their autistic child's IEP," which at that time resulted in many parents unilaterally withdrawing their children from state programs to begin home based ABA programs (Womack, 2002, p.2). This follows what Baker and Steuernagel (2009) identified as "the most successfully promoted (and contested) idea associated with autism

policy is the necessity of ABA as a treatment for autism as a disease similar to AIDS or cancer" (p.237). While ABA has significant empirical evidence, the nature of the IEP decision making process is such that parents and professionals are all provided a voice and seat at the table so as to collaboratively develop a program to meet the individual needs of a child, and in the case of ASD, there does not exist any one-size-fits-all perfect solution for treatment across the wide range of presenting cases. Thus, IDEA continues to support a focus on individual, case-by-case determination of what constitutes a FAPE for a given student (Womack, 2002).

Simpson (1995) commented that "meaningful parent-professional IEP collaboration must be based not on litigation contingencies, but, rather, on a partnership in which parents and educators work together for the child's good" (p.15). The IEP meeting serves several important functions. First, it is a communication vehicle between parents and school personnel to enable joint decision making in regards to a child's needs and services provided to meet those needs. Second, it provides an opportunity for resolution of differences between parents and the educational agency. Third, it specifies a commitment of resources to the child. Fourth, it is a management tool to ensure that a child with a disability is provided with services appropriate to their needs. Fifth, it provides a compliance/monitoring document in review of the child's receipt of a FAPE. Finally, it is an evaluation device used to monitor progress toward projected outcomes (U.S. Department of Education, Office of Special Education and Rehabilitative Services, 1992).

Some researchers consider the traditional IEP meeting to be a meaningless ritual

(Rock, 2000), as some educators unfortunately present the expectation that parents approve pre-determined programs (Fish, 2006, p.56). A lack of feedback and participation from parents in IEP meetings has been cited as contributing to the facilitation of "legally inappropriate and educationally unsound educational programs for students receiving special education services" (Fish, 2006, p.56). It is possible that this disconnect between the potential provided by the IEP meeting and the reality of its implementation is in part affected by the experiences expressed by parents, with many parents reporting feelings of guilt, intimidation, disenfranchisement, and alienation towards the educational system (Goldstein, 1993; Kroth & Edge, 1997), and with the perception by parents that IEP meetings are at times an "opportunity for educators to brief them on the failures of their child" (Fish, 2006, p.57). In Fish's (2006) case study of seven families with a child experiencing an ASD, all of the participants reported that their overall IEP meeting experiences had been negative, with most participants indicating a perception of negative treatment at some point by an educator during an IEP meeting, receiving blame for their child's behavioral and academic deficiencies. Also, participants reported being perceived by educators as unreasonable for requesting services that school districts deemed unnecessary or too expensive (Fish, 2006, p.61). However, over time, most participants reported improvement in their relationship with school personnel, citing the value of increasing their familiarity with their student's rights and the process as a central variable in the improvement of both relationship and services provided for their child (Fish, 2006, p.62).

Legal involvement. The inherent controversy and disagreement regarding the

efficacy and preference for specific treatments has resulted in cases where IEP teams found themselves unable to reach agreement, thus resulting in the invocation of due process (Heflin & Simpson, 1998b). Mandlawitz (2002) found that amongst state directors of special education and LEAs surveyed, few reported that policies specifically related to serving children with an ASD existed prior 1990. In review of the United States Supreme Court decision establishing a free, appropriate public education, Mandlawitz (2002) shared that courts have historically established appropriate services to be dependent upon a reasonable calculation providing some educational benefit (p. 496), although some cases have supported a cornerstone of the special education law, which calls for all students to have the right to an education that provides more than trivial benefit (Boomer & Garrison-Harrell, 1995; Heflin & Simpson, 1998b). Citing the United States Supreme Court's decision in a case between the Board of Education of the Hendrick Hudson Central School District v. Rowley, Heflin and Simpson (1998b) illustrated that the goal of the IDEA is to provide appropriate, but not necessarily optimal, special education.

The line between what constitutes trivial versus appropriate-but-not-necessarily-optimal special education is not easily discernable in the case of ASD. Heflin and Simpson (1998b) made the keen observation that "winning a case involving provision of services for young children with autism depends significantly on the use of qualified experts to support or refute the [local education agency's] program. Often these cases turn on 'dueling experts," who offer the perspectives of the party they represent…" (p.497). Clearly, professional disagreement over the efficacy of any given treatment for

individuals with an ASD is not limited to IEP team meetings; this is an area of contention that spans venues all the way to the Supreme Court. In the case of ASD, conflict regarding appropriate and/or efficacious treatment to be provided through IEPs complicated by many factors, leaving the path and the destination of successful and meaningful treatment design and delivery both as moving, ill-defined targets. The conflict that arises among educators, mental health providers, and families is often wrought with both professional and personal dogmas, further complicating the decision making process and challenging the focus on client-centered decision making.

Cost of services. To begin to understand the cost of treating, supporting, and caring for individuals experiencing an ASD, we must first examine our understanding and conceptualization of disability. In the western world, the concept of disability has in recent years moved away from the perspective that, "to be disabled was to be handicapped and therefore a locus for pity, perpetual supervision and, often, poverty" (Baker, 2006, p.17). This view has evolved into an understanding of disability in terms of the rights held by those with disability, in turn highlighting the importance of information reported by the individual in the process of developing and assessing related policies and programming (Baker, 2006). These contrasting understandings paint two disparate pictures in regards to how we conceptualize an individual with an ASD diagnosis, and also informs much of our expectations for the outcome of treatment and services. If we are to look at those with an ASD diagnosis as people defined by their disability, and thus, inherently disabled, we would likely envision a lifetime of intensive needs based services. In contrast, if we are to look at those same individuals as people

with a disability, and focus on outcomes that support the goal of increasingly independent life skills, we enable the services and policies supporting this population to achieve such goals.

The cost of providing treatment and care for an individual with an ASD is impressive not only in immediate financial demands, but also in terms of the broader impact that treatment and care have upon the parents and families who support them. Families may incur legal expenses in an effort to secure services, as well as experience a loss of productivity (Ganz, 2007). Families may find that the full expense of alternative therapies is not covered by insurers, and that interventions such as specialized diets also pose additional outlay (Ganz, 2007). There are also potential societal costs associated with those individuals for whom early treatment was insufficient or nonexistent, as exhibited through a loss of productivity as adults, need for intensive care, and limited to non-existent income. The productivity loss associated with an ASD diagnosis may account for as much as 31% over the lifetime for the individual, and 29% for their parents: $992,000 and $928,000, respectively (Amendah, Grosse, Peacock, & Mandell, 2011, p. 1358). Amendah and colleagues (2011) provided a review of current literature detailing these costs, and presented that medical expenditures per person range from $2,100 to $11,200, and represent 3% to 5% of the estimated total annual cost for a child with an ASD (p.1357). In comparison to peers of the same age, privately insured children with an ASD diagnosis exhibited a median medical expenditure 8-9 times higher than those without an ASD diagnosis (Shimabukuro, Grosse, & Rice, 2008, p. 549-550).

Beyond the immediate medical financial demands lie the non-medical costs that

represent perhaps the largest expenditures. Amendah and colleagues (2011) found that the annual price of educating a child with an ASD comes in around $13,000, and this only represents the allocation for special education. Intensive behavioral interventions, which are invariably a component of virtually any ASD treatment plan, may run between $40,000 and $60,000 per child, per year (Amendah et al., 2011, p. 1357). These figures for intensive behavioral interventions assume that the child continues to be educated and cared for in their local school environment; should the child require residential care, the estimates of cost range from $60,000 to $128,000 per year (Amendah et al., 2011, p.1357).

It is estimated that over the course of a lifetime, an individual with an ASD will spend twice as much of his or her own money on direct medical costs compared to the typical U.S. citizen (Ganz, 2007, p.348). In Sweden, estimates of the lifetime cost of ASD range from $1.3 million per person for individuals with a high degree of functioning to $4.7 million per person for those requiring significantly more care (Jarbrink & Knapp, 2001). The figures don't suggest much difference with the U.S., as Ganz (2006, 2007) estimated the mean per person lifetime cost for individuals with an ASD to be $3.2 million. The human side of these figures presents individuals who have the opportunity to have their own interests, relationships, and capacity for autonomy. In discussing the financial cost of care and services for individuals experiencing ASD, we must also take into consideration the opportunity cost for the individual; the life experiences that may be adversely impacted by limited social functioning and limited relationships, and the unexpressed potential for active participation within their lives and community. These

components are difficult, if not impossible to measure, and yet pose the greatest cost to an individual experiencing ASD and their families and communities.

Current efforts at the state level appear mostly around the development of task forces, commissions, and councils, with 26 states employing a task group created by their legislature or governor, and the remaining 24 without an active group (National Conference of State Legislatures, 2009). The work of task groups is often invaluable in providing clear, coherent recommendations for legislators and the public, however, as in the case of the state of Vermont's Interagency White Paper on Autism Services (McFadden & Bruno, 2006), these reviews of available knowledge and recommendations are limited in their impact and have not resulted in the establishment of policy requiring school systems to follow these recommendations. In fact, much of the legislative emphasis on a state level has focused on legislation related to ASD and insurance coverage, particularly the move to require private insurance companies to provide coverage for ASD treatment. As of January 2012, 29 states require insurance companies to provide coverage for ASD treatment (National Conference of State Legislatures, 2012).

Attention from the federal level in recent years has also echoed the state level efforts of the establishment of task forces, commissions, and councils, albeit with more emphasis on supporting research and applying greater resources. The Combating Autism Act of 2006 established the Interagency Autism Coordinating Committee, mandating a strategic plan for ASD research while providing nearly $1 billion in funding for five years of research, screening, treatment, and education (Interagency Autism Coordinating

Committee, 2009).

Summary

Educators, parents, and practitioners alike all face substantial challenges in the development of comprehensive, meaningful programming for students experiencing an ASD. In this chapter I have provided a brief review of many of the factors which contribute to this challenge: the variety of available interventions, issues that IEP teams face internally within their own collaborative process, the role that perception and belief play in personal investment in any given intervention, the importance of parental involvement and consideration for the role of the complex family system, and the public policy, legal, and clinical contexts for treatment decisions within public education.

While significant literature exists regarding the efficacy and role of the treatments and interventions available for children with an ASD, there is a relative lack of literature that describes the types of services actually being provided within specific contexts. This study addresses that need by describing and analyzing services provided for children with an ASD in public schools in Vermont, specifically examining what is being provided, how it is being implemented, and why these given interventions are supported by directors of special education.

Through examining these three research questions, I have provided a description of what services are typically offered to public school students with an ASD in Vermont, as well as a description of the implementation of these services. Additionally, a description of the processes informing the development of IEPs is explored through inquiry as to *why* these services are applied: information in general about the processes

that Vermont's 46 public school districts employ to support and inform their IEP development process.

Chapter 3: Methodology

Rationale for Study

The treatments available to children and adolescents with ASD are plentiful, and the decision process by which school systems and families determine what treatments to provide and how to provide them can be cumbersome at best, with research evidence, personal opinion, subjective lenses, cost, and available resources all coming into play. This study explored the question of what services are implemented and supported by schools or school districts for students with an ASD in Vermont, how decisions are made regarding service identification and delivery, and why some services and interventions are selected over others. I recognized that these three research questions were not immediately translatable into concrete survey questions, which lead to the development of intermediary questions that provided more specific areas of inquiry, stemming from the primary research questions. The following questions were considered in order to help formulate questions to be included in the survey, so as to help connect participants' responses to concrete examples pertaining to the research questions:

- What services/interventions are provided for children/adolescents with an ASD within your supervisory union?
- Why are these services/interventions applied to students with an ASD within your supervisory union?
- In general, how are services/interventions determined as applicable to students with an ASD?
- What internal and/or collaborative processes inform the decision making process to

determine services/interventions to be applied?

- What role does the child play in determining applied services/interventions?
- What role does the family's advocacy and input plan in determining applied services/interventions?

Research Design

I chose a qualitative research design for this study, because I sought to provide description and exploration of what is currently unknown: that is, the practices and decision-making processes behind ASD treatment in public schools in Vermont. Throughout the study, I describe what treatments, interventions, and services are provided and how they are being implemented. I also explore the reasoning behind IEP team decisions leading to these treatments, interventions, and services, and their implementation. I provide an account of this information through survey data containing open-ended, multiple choice, and Likert-scale questions, administered to directors of special education and those with equivalent titles involved in these decision-making processes. Creswell (1998) provided that "in a qualitative study, the research question often starts with a how or a what so that initial forays into the topic describe what is going on" (p.17). This is the primary rationale for the study's research design, as this study seeks to answer the questions of what, how and why. As the preceding review of the literature suggests, the topic of ASD services in Vermont is in need of exploration, as the "variables cannot be easily identified, theories are not available to explain behavior of participants or their population of study, and theories need to be developed," further, in exploration of this topic, detailed information must be gathered within the scope of a

natural setting (Creswell, 1998, p.17).

Milne and Oberle (2005) posit that "qualitative research seeks not to reveal 'truth' but to generate insights. Qualitative researchers aim to describe and understand the nature of reality through participants' eyes with careful and on-going attention to context" (Milne and Oberle, 2005, p.413). This study sought to generate insight into the gap between research and practice. Through an analysis of the reality described by the administrators participating in this study, insight may be derived to help describe how and why any gaps between research and practice exist. Milne and Oberle describe qualitative description as "a stand-alone method that affords a comprehensive summary of human experience without an in-depth level of interpretation," with the goal of staying "close to the surface of data while capturing all the elements of that experience" (p.413). I chose qualitative description so as to provide this comprehensive summary of human experience. Sandelowski (2000) presented that "qualitative description is especially amenable to obtaining straight and largely unadorned (i.e., minimally theorized or otherwise transformed or spun) answers to questions of special relevance to practitioners and policy makers" (p.337), a quality that adheres closely to the research problem of this study, as I collected direct answers to the basic questions pertaining to the what, how, and why of ASD services in Vermont.

Research participants. Miles, Huberman, and Saldana (2014) identified that sampling in qualitative research "involves decisions not only about which people to observe and/or interview but also about settings, events, and social processes" (p.30). Miles and colleagues identified two actions that at times appear to "pull in different

directions," the need to set boundaries, that is, "to define aspects of your case that you can study within the limits of your time and means, that connect directly to your research questions, and that probably will include examples of what you want to study," as well as the need to "create a conceptual frame to help you uncover, conform, or qualify the basic processes or constructs that undergird your study" (Miles et al., 2014, p.31). In the scope of this proposed study, significant data could have been sampled from a seemingly countless array of special educators, administrators, and so forth; however, this would have presented a great challenge to the limitations presented by time, means, and feasibility. In contrast, too limited a sample, both in terms of the number of participants as well as diversity across the state, would have compromised my ability to identify to consider my findings within a conceptual framework. In consideration of these two primary actions, the scope of this study lead to a purposeful sampling strategy: a focus on directors of special education and equivalent titles in the state of Vermont, allowing for any deviation in title to accommodate the functional lead administrator of special education services per each supervisory union as the targeted participant per supervisory union. Each of Vermont's supervisory unions/districts were included in the sample, for a total of 58 identified lead administrators of special education services receiving the survey. Access to each of these participants was gained through publicly available information via the Vermont Agency of Education website, as well as through direct contact with the Vermont Agency of Education (Vermont Agency of Education, 2010). As this is publicly available information, advance permission or other forms of recruitment were not necessary.

Survey development. The development of the online survey was supported by my literature review as well as informal consultation with professionals from the public mental health and public education sectors who are familiar with my proposed research. Consultation was facilitated by sharing a preliminary draft of my survey with chosen professionals in the fields of public education and public mental health, in support of refinement and revision of survey questions per others' shared experience and perspective. Through a shared discussion of my proposed research and drafted survey questions, I utilized the advice and perspective of other professionals to support the development of the final set of survey questions. I developed a mixture of open ended, multiple choice, and Likert-scale survey questions seeking responses that informed the aforementioned research questions and questions for analysis: information pertaining to what services/interventions are applied for students with an ASD in Vermont schools, how these services/interventions are implemented, and why these services/interventions are chosen; that is, information pertaining to the decision-making process informing service/intervention application. Participants were asked to identify services and interventions commonly utilized in service of students with an ASD, and to write in general about the implementation and treatment decision-making processes present within their districts. Responses to the open-ended survey questions were in the form of short narrative answers, producing data for content analysis within and across cases. Answers provided for the multiple choice and Likert-scale questions produced additional data for analysis, specifically in regards to identification of specific services/interventions provided, demographic data, and other finite details.

I developed my survey using the LimeSurvey online survey service, which gave participants an opportunity to provide as brief or as lengthy of an answer as they desired. Analysis of questions seeking to inform what services are provided across the state included the development of a list of identified services, which in turn provided specificity in the form of comprehensive identification of provided services.

Data collection. Surveys were made available to each of Vermont's 58 directors of special education and those with equivalent titles during the summer of 2013, which provided participants the opportunity to participate in the study during a period of time that administrators typically face fewer scheduling demands and challenges, and generally have more time available to attend to requests such as their participation in this study. In order to ensure a terminal date by which surveys would be returned and included in the study, a request to submit the survey by August 31st, 2013 was provided. I provided initial invitations to participate through email as well as postal service mail, so as to increase the likelihood that targeted participants will receive the invitation. I also provided email reminders at approximate one month intervals during the summer. I originally estimated that participation in this survey would require participants to allocate between 15-30 minutes of their time, dependent upon their choice of detail/brevity, and their personal efficiency in answering questions, typing, and so forth. The survey consisted of nine open-ended questions, four multiple choice questions, and three extended Likert-scale questions. It should be noted that four of these questions were simple demographic questions.

Data analysis and synthesis. Data analysis consisted of a process of content

analysis in order to utilize procedures in effort to make valid inferences from the textual data (Weber, 1990, p.9), utilizing the software program HyperRESEARCH for support through this process. Weber has noted that content analysis can be used to code survey data, including open-ended questions, as well as to identify and describe trends in content (p.9). Content analysis is reported to carry several advantages over other data analysis techniques; in the context of this study, content analysis' strengths through operating directly on text of human communications as well as its yielding "unobtrusive measures in which neither the sender nor the receiver of the message is aware that it is being analyzed," thus minimizing the danger of measurement affecting the data (Weber, 1990, p.10).

Within the process of content analysis, coding and cross-case analysis were utilized to identify themes within and across participant responses. Miles et al. (2014) described coding as a "data condensation task that enables you to retrieve the most meaningful material, to assemble chunks of data that go together, and to further condense the bulk into readily analyzable units" (p.73). In my research, coding consisted of a set of inductive codes developed during the process of review and analysis of the data. The preliminary analysis of the data provided the ability to develop a set of inductive codes for each of the qualitative questions posed in the survey, with inductive coding further refined through successive passes and review of the data. This process of developing a preliminary list of inductive codes during the initial analysis, and then informing the established codes through recurrent analysis and development of additional inductive codes, occurred during the initial cycle of coding each of the surveys, with further

refinement taking place with successive cycles of coding.

Miles et al. (2014) asserted that cross-case analysis provides the advantage of increased generalizability, identifying that events and processes identified within one setting are not idiosyncratic. In this study, cross-case analysis was utilized for these reasons, while also serving the primary goal of looking for common themes across any of the available data. Given that each respondent was aligned with a unique school district or supervisory union with its own context and local practices, I considered each respondent to constitute a case.

In order to provide a visual representation of the process of cross-case analysis, a partially ordered display was used to provide internal order while making the data comparable through standardization into a single metric (Miles et al., 2014, p.136). Development of a partially ordered display was supported through my use of HyperRESEARCH in the intra-case analysis and coding process. Through utilizing computer software to conduct analysis and coding from the beginning of this process, I was able to produce limited quantified data regarding the rates of incidence of inductive codes within specific cases, as well as the rates of incidence of inductive codes across cases. Use of analytic software also supported the identification of themes across cases on the basis of approximate district size, geography, and the other demographic data received. Additionally, the use of an easily adaptable software program for data management permitted the visual representation of common themes identified across cases, further supporting the analysis of available data.

Ethical Considerations

In my development of this study's survey, I was aware that such a survey would encounter risks to student confidentiality as a result of inquiring about practices implemented with the students in any given school. I was able to avoided many ethical challenges in this area by querying participants about practices in their supervisory union across all students: No specific student's IEP or specific programming was requested or would have been applicable for the provided survey questions. Issues of individual privacy and confidentiality of students were avoided, as no individually identifying information is discernable from the collected data.

Upon reviewing the statement of informed consent contained within the information provided as part of the LimeSurvey survey, participants indicated provision of informed consent through voluntary participation past the introductory page. Rather than utilize a documented informed consent page, which would leave personally identifying information in the otherwise anonymous survey, the request to waive the documentation of informed consent was applied to protect the confidentiality of participants. Participants learned through the introduction to the survey that their confidentiality is protected through the LimeSurvey service, as answers to completed surveys are anonymous: a registration token is required only for initial access. The informed consent document included information regarding voluntary withdrawal from the study, which may have been chosen simply through nonparticipation. Each invitation was sent to specific intended participants by name, with a token identifier included in the invitation email and postal service invitation. Identifying information pairing each participation token and an individual's identity existed solely within the LimeSurvey

database, however, answers to completed surveys were established as confidential from within the online survey's construction. Eliminating any connection between the identity of participants and their corresponding participation token and the answers provided in the online survey effectively removed any connection between a participant's answers and their otherwise hidden identity. As an additional measure of protection to participants, their identities and participation status were protected through the LimeSurvey database, which maintains confidentiality through password protection and online security measures.

Issues of Credibility

As is likely the case for many researchers, my interest in the topic of this study was born of first hand professional experience. During a four-year period of time working for a school-based services program contracted to provide behavioral support and treatment in school settings, I frequently found myself navigating the topic of services and treatment provided for students with an ASD. I learned a great deal from educators, parents, and mental health providers in regards to treatment philosophy, available resources, and implementation.

Through the experiences I gained through my work in public school environments, I discovered that the services provided for students with an ASD did not always reflect the recommendations yielded by the research literature, nor did these services consistently reflect a response to the presenting needs of a given student. At times, some students did receive services and supports as indicated by their unique presentation and challenges, including interventions supported in research literature.

Specific cases I worked on presented their own unique reasons for why a student might not receive services indicated by their presenting needs, or by ASD in general; however, these specific cases did not allow me to draw more general conclusions. The dividing line between students who received services as indicated by their needs, versus those who received services that were not parallel to their presenting needs, remained opaque to me, and led me to conduct this study.

My experiences in research-based, public mental health programs led me to develop biases in favor of research-based interventions; biases which were then challenged through other personal and professional experiences in which I came to observe positive impacts by interventions lacking a research-base. In this time I also observed long-term negative outcomes resulting from the application of some interventions, which at times supported the hope and faith of families while providing a negative or ineffective change for the child experiencing ASD. These experiences led me to a position where I chose to employ a critical lens in looking at interventions for ASD, and to apply a functional analysis in considering the application of any given service or intervention for a child and/or their family. In developing the survey questions for this study, I sought to employ the support of colleagues in the field of public mental health and ASD treatment to avoid the biases I have held, and to allow myself, and the study, the benefit of feedback from individuals from differing perspectives on the topic of ASD services.

To further mitigate potential biases through the process of coding and analysis, I utilized the support of a mentor and previous colleague to review my coding scheme and

to then apply the coding scheme to a limited number of surveys. In doing this, I sought to inform the consistency and agreement of the application and interpretation of these codes by reviewing my own interpretation and application with that of others familiar with my work. In a method similar to external review, I turned to a former colleague to discuss emerging themes identified during the analysis and coding process, so as to ensure that my analysis was consistent with others' perspectives and interpretation.

Chapter 4: Findings

I have divided my findings into two categories: first, the demographic and other data collected through multiple choice questions, and second, the open ended questions provided to participants. Of the 58 directors of special education and/or those with equivalent titles sampled, 27 individuals responded, with eight of those responses presenting significantly incomplete data: leaving 19 complete responses that were included in the study. Considering only complete responses, a response rate of 32.76% was obtained in this study. Of these 19 participant responses, the majority of participants identified as working in medium sized districts, and the remainder identified as working in small districts. Gender was not included in demographic questions, and further information regarding demographic and background information of this study's participants is included in Tables 1 through 5.

Following the description of these data I will identify themes that are emergent through cross-case analysis of the open-ended questions, including applicable data gathered through the demographic and multiple choice questions.

Demographic and Background Information

As shown in Table 1, 63.16% of participants in this study described the size of their district in regards to population as medium sized, with 42.11% describing the population size of their district as small, and no participants identifying their district as having a large population. This question may be interpreted as assessing the participants' perception of their population size. No parameters were provided identifying what constitutes a small, medium, or large population size.

Table 1

How Would You Describe the (population) Size of Your District?

Small	Medium	Large
42.11%	63.16%	0.0%

Descriptions of the geographical size of participants' districts were similar, with 21.05% reporting a small geographical size, 73.68% describing their district as encompassing a medium-sized area and 10.53% reporting a large size of their district, as reflected in Table 2. In parallel with Question 1, this question may be interpreted as providing information more accurately describing the participant's perception of the size of their district, as no parameters for what constitutes a small, medium, or large district were provided.

Table 2

How Would You Describe the (geographical) Size of Your District?

Small	Medium	Large
21.05%	73.68%	10.53%

Table 3 indicates that 63.16% of respondents reported seven or more years of experience in regards to implementing interventions for students with ASD, 31.58% reported four to six years of experience, and 10.53% reported one to three years of experience.

Table 3

How Would You Describe Your Professional Experience in Regards to Interventions for Students with Autism Spectrum Disorders?

Some Experience (1-3yrs)	Moderate Experience (4-6yrs)	Significant Experience (7+ yrs)
10.53%	31.58%	63.16%

In reporting their professional training in regards to interventions for students with ASD, Table 4 reflects that 68.42% reported moderate training, including graduate level coursework; 31.58% reported some training in the form of undergraduate coursework, conferences, and brief trainings; and 5.26% reported significant training in the form of a concentrated program of study.

Table 4

How Would You Describe Your Professional Training in Regards to Interventions for Students with Autism Spectrum Disorders?

Some Training (undergraduate coursework, conferences, brief trainings)	Moderate Training (graduate level coursework)	Significant Training (concentrated program of study)
31.58%	68.42%	5.26%

As shown in Table 5, 42.11% of participants served zero to ten children with an ASD in their districts, 31.58% served 11 to 20 students, 21.05% served 21 to 30 children, and 10.53% served 41 to 50 with ASD.

Table 5

Approximately How Many Children with Autism Spectrum Disorders are Served in Your District?

0-10	11-20	21-30	31-40	41-50
42.11%	31.58%	21.05%	0.0%	10.53%

Table 6 depicts information regarding the utilization of 26 different interventions that may be provided for students with an ASD, with frequency data reported for each. Interventions on this list are associated varying degrees of support found in literature on ASD interventions, for example, those identified by the National Autism Center (2009) in their standards report as either unestablished, emerging, or

established treatments with favorable outcomes reported. In Table 18, the data from Table 6 is collated and exhibited according to each intervention's corresponding level of support, as provided by the National Autism Center's standards report.

Table 6

Please Identify Any of the Interventions Described Below That Are Provided to Students with an Autism Spectrum Disorder in Your District, and Rate the Approximate Frequency of Use for Each Intervention:

Intervention	Never	Seldom	Occasionally	Regularly	No Response
Academic Interventions	0.0%	0.0%	5.26%	94.74%	0.0%
Auditory Integration Training	31.58%	31.58%	21.05%	10.53%	5.26%
Facilitated Communication	36.84%	21.05%	31.58%	10.53%	0.0%
Sensory Integration	0.0%	0.0%	26.32%	73.68%	5.26%
AAC Devices	0.0%	10.53%	26.32%	63.16%	0.0%
Cognitive Behavioral Intervention	0.0%	10.53%	47.37%	42.11%	0.0%
Developmental Relationship-Based Treatment	21.05%	21.05%	15.79%	21.05%	21.05%
Imitation-Based Interaction	15.79%	21.05%	26.32%	31.58%	5.26%
Language Training (production and/or understanding)	0.0%	5.26%	5.26%	89.47%	0.0%
Massage/Touch Therapy	63.16%	31.58%	0.0%	0.0%	5.26%
Music Therapy	63.16%	31.58%	0.0%	0.0%	5.26%
Peer-Mediated Instructional Arrangement	47.37%	36.84%	10.53%	0.0%	5.26%

PECS	0.0%	5.26%	21.05%	68.42%	0.0%
Scripting	10.53%	10.53%	31.58%	47.37%	0.0%
Social Skills Training	0.0%	5.26%	10.53%	84.21%	0.0%
Theory of Mind Training	26.32%	15.79%	36.84%	21.05%	0.0%
Applied Behavior Analysis	5.26%	5.26%	36.84%	52.63%	0.0%
Other Behavioral Intervention(s)	0.0%	15.79%	21.05%	42.11%	21.05%
Joint Attention Intervention	26.32%	26.32%	31.58%	5.26%	10.53%
Modeling	0.0%	10.53%	15.79%	73.68%	0.0%
Naturalistic Teaching Strategies	42.11%	15.79%	5.26%	21.05%	15.79%
Peer Training	31.58%	31.58%	36.84%	0.0%	0.0%
Pivotal Response Treatment	42.11%	31.58%	5.26%	5.26%	15.79%
Schedules (textual or pictorial)	5.26%	0.0%	0.0%	94.74%	0.0%
Story-Based Intervention (e.g. – Social Stories™)	5.26%	5.26%	5.26%	84.21%	0.0%
Self-Management	5.26%	10.53%	15.79%	68.42%	0.0%

Table 7 provides reported frequencies of utilization of indirect and/or supportive interventions for students with an ASD.

Table 7

Please Identify Any of the Indirect and/or Supportive Interventions Described Below that are Provided for Students with an Autism Spectrum Disorder in Your District, and Rate the Approximate Frequency of Use for Each Intervention:

Intervention	Never	Seldom	Occasionally	Regularly	No Response

Behavior Consultation Services (internal staff)	5.26%	0.0%	5.26%	89.47%	0.0%
Behavior Consultation Services (outside providers, e.g. local mental health agencies)	10.53%	0.0%	31.58%	57.89%	0.0%
General Autism Consultation Services (internal staff)	5.26%	15.79%	26.32%	52.63%	0.0%
General Autism Consultation Services (outside providers, e.g. local mental health agencies)	0.0%	21.05%	21.05%	57.89%	0.0%
Occupational Therapy	0.0%	0.0%	10.53%	89.47%	0.0%
Physical Therapy	0.0%	15.79%	26.32%	52.63%	5.26%
Speech and Language Services	0.0%	0.0%	0.0%	100.00%	0.0%
Supports for the Home Environment	5.26%	15.79%	47.37%	31.58%	0.0%

Table 8 provides information regarding the respondents' perceptions of the

influence of various individuals in the IEP decision-making process involved in identification of interventions for students with an ASD in their district. Within Table 8, it exhibited that 10.53% of respondents indicated that student self-representation has no influence in the decision-making process, 41.11% reported a mild influence, 26.32% reported a moderate influence, and 21.05% reported a strong influence. In contrast, 89.47% of respondents reported that parents have a strong influence in the decision-making process, and 10.53% of respondents reported that parents have a moderate influence. It may be important to note that in some cases, student self-representation would have no influence under any circumstances, as such self-advocacy is not typical or necessarily appropriate for certain individuals or certain age groups. Outside advocacy groups were identified primarily as having a mild influence (47.37% of respondents). Special education case managers were reported as having a strong influence on the process (78.95% of respondents), with 21.05% of respondents reporting a moderate influence. Both internal and external consultation services were identified as having a strong influence by 63.16% and 52.63% of respondents, respectively. Special education administration members and paraprofessionals were both reported as having a moderate influence (47.37% of respondents).

Table 8

How Would You Describe the Degree of Influence of Persons Holding Each of the Following Roles in the IEP Decision-Making Process that Determines Identification of Particular Interventions for Students with an Autism Spectrum Disorder?

	No Influence	Mild Influence	Moderate Influence	Strong Influence

Student Self-Representation	10.53%	41.11%	26.32%	21.05%
Parents	0.0%	0.0%	10.53%	89.47%
Outside Advocacy Groups	10.53%	47.37%	36.84%	5.26%
Special Education Case Managers	0.0%	0.0%	21.05%	78.95%
Consultation Services (internal)	0.0%	5.26%	31.58%	63.16%
Consultation Services (external)	5.26%	10.53%	31.58%	52.63%
Special Education Administration (directors, coordinators, etc.)	0.0%	21.05%	47.37%	31.58%
Paraprofessionals	5.26%	36.84%	47.37%	10.53%

Open Ended Questions

The following subsections describe each of the open ended questions presented to survey participants, as well as the prevalent, recurrent content identified by participants. Data identifying the frequency of coded responses is provided in conjunction with narrative description for each question below. Further descriptive information pertaining to the codes identified may be found in Appendix A.

Use of data collection and analysis. Question 1 asked respondents to describe what, if any methods of data collection and analysis were employed as part of their direct instructional intervention(s) for children in their district with an ASD.

Table 9

Question 1: Please describe what, if any methods of data collection and analysis are

employed as part of the direct instructional intervention(s) identified in the previous question:

Code	Number of Occurrences
Behavior Interventionist taking data	2
Individual, daily data	20
Monthly review of data	2
Answers that do not explicitly specify what methods of collection and/or analysis are employed	6
School-based progress reports, including IEP	5
Therapy notes	1
Weekly review of data	2

In their responses to this question, reference to individualized, daily data collection appeared 20 times. This information potentially presents an indication of the understanding of the role that individualized treatment plays for individuals with an ASD. One respondent indicated that they currently utilize external service providers specializing in ASD services, and that these 1:1 staff provide daily data collection, which may suggest a more robust and data driven program for this district's children with ASD. Another respondent indicated that their district provides "charting of specific behaviors, token systems, and academic tests," with documentation of "all minor and major behaviors" which are then charted according to in daily, weekly, and monthly intervals. Descriptions such as these suggest extensive programming, a contrast from other responses that provided limited or nonexistent information pertaining to specifics of data collection and analysis, in some cases simply referring to standard IEP practices such as progress reports.

Assessment tools used to guide program development. Question 2 asked participants, what, if any, specific assessment tools are employed to guide the

development of a student's program, for example, diagnostic, developmental, adaptive, communication, and intelligence assessments such as the Autism Behavior Checklist, Psychoeducational Profile-Revised, Vineland Adaptive Behavior Scales, and the Reynell Developmental Language Scales.

Table 10

Question 2: What, if any, specific assessment tools are employed to guide the development of a student's program? (e.g. - diagnostic, developmental, adaptive, communication, intelligence, assessments such as the Autism Behavior Checklist, Psychoeducational Profile-Revised, Vineland Adaptive Behavior Scales, Reynell Developmental Language Scales, respectively)

Code	Number of Occurrences
ASD specific assessment tool(s)	15
I don't know	2
No ASD specific assessment tool(s)	5
Vague answer(s), not identifying a specific assessment tool	5
Supplemental assessments such as those commonly provided by Occupational Therapists, Physical Therapists, Speech and Language Pathologists, and/or School Psychologists.	19

In their responses to Question 2, supplemental assessments such as those commonly provided by Occupational Therapists, Physical Therapists, Speech and Language Pathologists, and/or School Psychologists were identified in 19 instances, overshadowing the 15 instances where ASD specific tools were identified. Additionally, responses that identified that no ASD specific assessment tool(s), or vague answers that did not identify a specific assessment tool, were each provided five times. In two instances, respondents' reported that they did not know what or if any assessment tools

are used in the development of a student's program.

In one example, a respondent identified that while no ASD specific tools are employed, other tools such as those utilized in special education are used, and that "if necessary, the Licensed School Psychologist can administer Autism Behavior Checklists and any Adaptive Behavior Scales." This response may present an area of further interest, as School Psychologists may not typically encounter education and training specific to ASD and the specialized treatment involved, as was the case when I completed a master's degree in Clinical Psychology with the option to pursue endorsement as a School Psychologist. Also, the current standards for School Psychologists set forth by the Vermont Agency of Education (2014) do not identify ASD specific training as part of their requirements for endorsement (p.123). It is worth noting that the Vermont Agency of Education takes a non-categorical approach to licensure, thus ASD and other specific diagnoses and/or categories are mentioned specifically. The relatively high rates of ambiguity or explicit lack of ASD specific assessment present areas for further discussion in the following chapter.

Positions responsible for conducting assessments. Following Question 2's inquiry regarding what, if any, assessment tools are utilized in the service of students with an ASD, Question 3 asked respondents to identify the position(s) of individuals responsible for conducting assessments.

Table 11

Question 3: What are the position(s) of individuals responsible for conducting assessments?

Code	Number of Occurrences
Board Certified Behavior Analyst	4

Center for Disease Control and Prevention	1
Physician / Psychiatrist	3
Generally identified behavior specialist without identified qualification(s)	2
Occupational Therapist, Physical Therapist, and/or Speech and Language Pathologist	20
Paraprofessional	1
School Psychologist	15
Special Educator	12

Occupational Therapists, Physical Therapists, and Speech/Language Pathologists were identified as the predominant roles of persons responsible for conducting assessments, with 20 cumulative instances provided by respondents. In the case of Occupational Therapists and Physical Therapists, professionals in these positions provide supplementary services that support specific progress in comorbid difficulties in areas such as employment/daily roles and activities, motor coordination, and sensory differences rather than primary modes of treatment for individuals with an ASD (American Occupational Therapy Association, 2008; Levy & Hyman, 2008). The scope of practice for Speech-Language Pathologists is different than that of Occupational or Physical Therapists, due to their central role in the process of providing assessment, diagnosis, and treatment (American Speech-Language-Hearing Association, 2015). The American Speech-Language-Hearing Association (2015) also identifies the important of interdisciplinary collaboration in treatment and assessment of an individual with an ASD, identifying "ideally, the role of the SLP is as a key member of an interdisciplinary team whose members possess expertise in diagnosing ASD" (Role of the Speech-Language Pathologist With Respect to Diagnosis). The services provided by these professionals are frequently important and central in addressing functional challenges an individual

experiences in their education and ability to access education; the frequency of the code referring to OT/PT/SLP may suggest an area of further inquiry regarding the makeup of teams relying upon these positions for assessment.

References to the Center for Disease Control, Physician/Psychiatrist, and Board Certified Behavior Analyst reflect utilization of providers who are typically central to the diagnostic/assessment process in the United States. Comprehensive diagnostic evaluations are performed by specialists including Developmental Pediatricians, Child Neurologists, and Child Psychologists/Psychiatrists (Centers for Disease Control and Prevention, 2015), and also may include objective assessment provided by a Board Certified Behavior Analyst (Behavior Analyst Certification Board, 2014).

Role of external consultation in individualized program development.

Question 4 asked respondents to share what role, if any, external consultants such as those provided through public mental health or private organizations play in the development of a student's program. This question may provide some insight into districts' utilization of external service providers and specialists in their development of treatment programs.

Table 12

Question 4: What role, if any, do external consultants (via public mental health or private organizations) play in the development of a student's program?

Code	Number of Occurrences
Consultation and staffing	3
Heavy dependence on outside consultation	3
Support for families at home	1
Individual program development	10
Occasional and/or minimal utilization of consultation	6
Training for staff	5

Supplemental services such as Occupational Therapy, Physical Therapy, etc.	1

In responses to Question 4, a balance between utilization of external consultation and staff was observed, with ten instances where respondents indicated that external consultation is utilized in the development of individual students' treatment programs, three instances indicating a heavy dependence on outside consultation, and three instances of utilization of consultation and staffing. In contrast, the responses that indicated consultation is utilized primarily in support of training and professional development for school staff, for home supports, and otherwise indicated that only occasional and/or minimal consultation is utilized, may suggest that these districts are developing and/or utilizing their own internal capacity for the treatment of students with an ASD.

In one example, a respondent indicated that external consultants provide the IEP team with reports; however, they do not participate in the development of plans due to "excessive conflict among the IEP team, parents, and the consultant." In contrast, another respondent wrote that "external consultants play an important role in the development of specific students' programs. The reason we contract with them is to assist us with the development of appropriate and effective teaching strategies and behavioral programming," providing insight into the school's awareness of the demands and specificity of training indicated in the service of students with an ASD. Yet another respondent shared that their district utilizes a mixture of in-house and external supports, identifying that they had several staff members with experience and training in ASD

programming, as well as ongoing contracts with their designated mental health agency and another local provider for Behavior Interventionist services and behavioral consultation. In a one example, a participant identified a lack of availability of providers within their region, identifying **"**We use the I-team. Mental health only provides a case manager and that person usually works as an advocate for the family and offers nothing else. There are no other providers we can access in our region." Additionally, some participants identified that the individualized nature of programming leads the decision of whether or not to utilize external consultation:

> We have some children where there is no external consultation because it is not necessary for the development of those children's programs. Other students with more complex or specific needs require expertise that my staff do not possess, in these instances the IEP team makes the request for consultation by an external party. This then may be for team meetings meeting to discuss possible solutions with the team only.... all the way to direct service time for developing specific pieces of a program along with specific training of the staff for implementation.

Qualifications of external consultants. Question 5 asked participants to describe whether or not internal or external consultation was utilized and what certifications consultants held in reference to these roles. This question provided an opportunity to examine the respondents' awareness of the specialization and training indicated for services for students with ASD, and how/if their district's practices utilized and/or identified the need for professional certification and development.

Table 13

Question 5: If consultation (internal and/or external) is utilized, what certifications or

related qualifications do the consultants carry (in reference to their roles, not specific individuals)?

Code	Number of Occurrences
Autism specialist (non-certified, informal title)	3
Board Certified Behavior Analyst	7
Medical degree	1
No certification or qualification, no answer, and/or an unofficial or unrecognized certification/qualification.	12
Occupational or Physical Therapist	7
Paraprofessional	1
School Psychologist	3
Speech/Language Pathologist	4
Special Educator	3

It is potentially significant that the most prevalent code found under Question 5 revealed that respondents identified either a lack of certification/qualification, or provided a non-answer in identifying the qualifications carried by either internal or external consultants for ASD services. As discussed previously, ASD treatment is known for incurring significant expense and requiring a significant amount of resources and attention. A potential disconnect between administrators' awareness of the qualifications and/or a lack of qualification for the intensive, specific work involved in ASD treatment may present a significant area of interest in this study's discussion.

Identification of consultants holding the title of Board Certified Behavior Analyst and Occupational/Physical Therapist were provided in seven instances. School Psychologist and Special Educator were identified three times, and Medical Doctor once. In each of these three latter examples as well as in the example of Speech and Language Pathologists, I found professional titles that do not implicitly convey any specific degree of training, experience, or knowledge regarding ASD; however, some individuals in these

professional roles do pursue specialized training in the field.

It may be a point of interest in that the title of Autism Specialist was identified in three examples, as this is not an officially recognized or professionally regulated title. Autism Specialist is typically found as a job title; however, requirements and description of this duties of this role have been anecdotally observed to vary greatly from situation to situation. Additionally, persons acting in the role of a school paraprofessional do not typically hold qualifications or training indicating appropriateness to serve as a consultant for ASD treatment and/or program development. Many responses included statements that suggested a lack of awareness/knowledge of this topic through language that utilized common, but unspecific terminology such as "license" without specifying what license the consultant may hold. The frequency of instances where unregulated positions and/or roles that do not implicitly carry any direct relevance to the consultation regarding ASD services presents an area of interest to this study, with continued discussion regarding this in the following chapter.

How programs are designed. In Question 6, participants were asked to provide information regarding how programs for students with ASD are typically designed.

Table 14

Question 6: How are programs for students with Autism Spectrum Disorders typically designed?

Code	Number of Occurrences
Assessments and/or data used to inform intervention	8
Collaboratively with the team	8
Working with the family	4
On an individual basis	12

An answer that does not identify how programs are developed.	8

Question 6 revealed 12 instances where respondents identified references to individually designed programs in the development of programs for students with ASD. This is potentially significant and may reflect respondents' awareness of the individualized nature of ASD programming. One example also identified access to general education and the balance between inclusion vs. exclusion as being hindered by past experience with generalized programming:

> Our approach is to look at each child individually, rather than have one program to fit all students. We had programs like that in the district and it restricted access to general education curriculum and social skills development. Since 2009 each child with suspected or known ASD receives thorough evaluation to determine academic ability, social skills ability and communication ability. From that evaluation the student's program is developed to support areas of need and support participation with typical peers. This has been a very successful model, leading to full participation with general educations for most of our students with ASD. Only a couple students are unable to be with their peers for extended periods of the day. The supervisory union as a whole no longer thinks about children with ASD as outsiders. They are for the most part fully included.

In contrast, another participant identified that their ability to host a larger program provided capacity for students who are not mainstreamed to receive specialized intervention:

> We host a regional program and those programs are designed by a team of the ABA special educator, a special educator who specializes in augmentative communication, and SLP, a vocational special educator and a curriculum special educator, OT and PT. We also use the PACT as a curriculum framework. For the mainstreamed students we use lots of social thinking curriculum, some ABA consult, lots of technology (iPads).

Eight instances identifying assessment and/or data driven processes informing intervention were provided, as well as eight instances identifying that collaborative work with a team inform the process. These areas all represent salient points within literature regarding best-practices for ASD programming, and may be interpreted as being representative of awareness and common practice amongst the respondents work within their respective districts.

It may be of note that in four instances it was mentioned that a child's family was included in the process of designing programs. Additionally, eight instances were found where the answer provided did not identify how programs are developed. The lack of mention of familial involvement presents an area of interest to this study as involvement between schools and families are an important area of treatment collaboration and coordination. Additionally, the stated lack of awareness of how programming is designed presents further questions regarding why a respondent would not be involved or informed regarding this aspect of practice.

Strength in current practices. Question 7 asked participants to identify what

aspects of their district's current practices would be described as strengths in the development, implementation, and evaluation of instruction and intervention for students with an ASD.

Table 15

Question 7: What aspects of your district's current practices would you describe as strengths in the development, implementation, and evaluation of instruction and intervention for students with an Autism Spectrum Disorder?

Code	Number of Occurrences
Supportive Administrative structure/individuals (superintendent, etc.)	4
Collaboration	1
Early intervention programs and support	1
Evidence based practice	2
Evaluation and assessment	1
Collaboration with external consultation	6
Focus towards inclusion and independence	4
Internal consultant	1
Regular meetings by teams	2
The model of treatment and intervention	3
Identifies that the district is learning, engaging in development	8
Staffing	8
Support for individuals in transitional stages	1
Having a variety of interventions available	2

Answers provided to this question were distributed across 15 separately identified codes, with ongoing professional development and quality of staffing each receiving the most identified occurrences at eight instances each. One enthusiastic respondent identified that their district's strength lies in "STAFFING!! Professional development and utilization of outside resources. Collaborative model with our mental health consultants and the ability to have staffing provided through that collaboration.

An extremely supportive supervisory union board! An extremely supportive superintendent!"

Collaboration with external consultants followed professional development and staffing with six identified occurrences, and a focus on inclusion and independence with four occurrences. A supportive administrative structure and supportive individuals within the administration were identified in four instances as being strengths, and three mentions of the implemented model of treatment were also identified. Two instances of identifying evidence based practice, a variety of available interventions, and regular meetings by teams, were each provided.

In one example, a respondent identified that their district's strength resides within their administrative structure supporting students:

> We currently have a clinical ASD team that reviews all ASD cases and supports screenings and evaluations across the district. The team receives referrals from the field to support individual teams. We also have clinical team members attend our intensive teams weekly to support programming with an eye towards inclusion and student independence.

Perceived challenges with current practices. In identifying challenges perceived by participants in regards to their district's current practices regarding students with ASD, 13 areas of challenge were identified, with the training of staff leading with 10 mentions.

Table 16

Question 8: What challenges do you perceive in regards to your district's current practices regarding students with Autism Spectrum Disorders?

Code	Number of Occurrences
Exclusionary attitude(s) towards students with an ASD	2
Geographic distance and accessibility	1
The need for more support for families	5
Lack of financial resources	5
The lack of independence demonstrated by a student	1
Individualized nature of ASD services	1
Lack of enough trained personnel	3
Small number of students with an ASD	1
Ability to sustain services from an early age through transition out of public school.	1
Ability to keep up with technology that can be used to support students	1
Time	5
Training for staff	10
Issues pertaining to the transition of students out of public school into independent adulthood	2

The constraints imposed by time, the need for more support of families, and the constraints of financial resources were each identified five times by respondents, with training appearing in 10 instances as well. One respondent identified that they "do not have enough trained personnel to be ahead of the curve. Time is always at a premium." Similarly, another reported "The need to have more staff trained, especially paraprofessionals. Funding! We cannot afford to lose the support required to keep staff trained…" The lack of time and funding was identified in some examples as having an impact on parents, as well, for example:

> A lack of community resources for parents continues to put added pressure on schools to be all things to families with Autism. While staff are willing to go above and beyond for these families, there is a limit in time and funding as to

what the schools can provide.

Similarly, another respondent identified the importance of continuing supports and interventions when school is not in session: “Families need supports outside of school. They need BCBA consultation and trained staff to assist their children at home, in the community. Especially over school breaks.”

Issues pertaining to the transition of students out of public school into independent adulthood, as well as the exclusionary attitudes towards ASD students were each identified twice. This concept of attitudes and inclusion is important in consideration of laws such as the IDEA, which support students’ rights to a least restrictive environment and inclusion within their peer groups. Statements such as “Attitudes of the regular education teachers who do not see them as part of the their class and therefore do not invest in the student's learning” identify a departure from attitudes and legal imperatives in the mindset of some educators, which one respondent identified as a training issue as well as being complicated by what they see as an unrealistic expectation:

> Significant lack of training in both regular ed and special ed teachers. Some of that is based on not having the perspective that these are everyone's students. Some of it is the unrealistic idea that our current system can fully and appropriately meet all needs.

In addition to training, perspectives of educators, and funding, some respondents identified systematic and administrative challenges. One reported that:

> We do not have a uniform system of supports for students with ASD across the

SU. Instructional programming varies depending upon the staff and resources available. Too many students with ASD have limited access to general education and receive most of their instruction from paraeducators.

Another commented:

State information, Physicians and Vermont Family Network continue to have old information about best practices for ASD interventions that cause conflict between families and district in a few cases. There are times we are fighting the tide because of old practices being shared with families. Our services and supports have been highly successful. When we are put in the position to disagree with one or a few of these entities it can derail the student's progress and success.

Possibilities for future improvement. Question 9 asked participants to share what they would like to see happen for their district in regards to the specific services and/or interventions and the decision-making process around service/intervention development for students with an ASD.

Table 17

Question 9: What would you wish to see happen for your district, in regards to the specific services/interventions and the decision-making process around service/intervention development for students with an Autism Spectrum Disorder?

Code	Number of Occurrences
Improvements around staff's attitudes towards students with an ASD	3
Collaboration between service providers and school	3
Additional consultation available	1
Stronger data collection/tools	2
Implementation of evidence based practices	1

Evaluation and assessment leading to instructional direction	2
Availability/access to funding for services	2
The respondent is content with current services	1
Additional professional development and training	8
Would like to have a specific program for students with an ASD	2
More physical space	1
Increased degrees of oversight from the Department of Education	1
Trained individuals to provide support/consultation for teachers and families	5
Support for students in transition out of public school into the community	1

Of the 14 items identified in the coding of this analysis, one respondent identified as being happy with the current state of services in their district, claiming that what is happening now is what they wish for. Eight responses mentioned a need for additional professional development and training, followed by five responses regarding a need for trained individuals to provide support and/or consultation for teachers and families. In regards to staffing, training, professional development, and inclusion related issues, a few respondents noted the need for systematic and state-driven supports:

> We are eager to have more interagency plans for our students with ASD - and are heading in that direction with a couple of our younger students. By building a community of support/services as early as possible, we hope to decrease stressors for the family and student and increase resources that will be available 24/7.

Another commented that:

As for decision making I wish the state would survey SU's to see what innovative practices are happening around the state. It is disheartening to know children continue to be placed in ASD programs with limited access to peers and curriculum because they exhibit ASD behaviors or social interactions. I wish the state would also review the quality of some of the external consultants who rely on punitive practices (seclusion and restraint) as the basis of their ABA programs. I am always amazed there is not a review structure for these services for children and adults on the autism spectrum within the state. Some private ABA consultants cause great conflict between families and school districts.

Still another mentioned that:

A common sequence of training and common orientation would be an excellent step for us. We do have lots of resources and expertise, but due to the stress inherent in meeting the needs for students with ASD and their families, the teams want us to hire one person to be responsible for it all I think, in part, so that they feel less guilty about all of the things that they cannot do for each student.

The theme of attitude and inclusion appeared again in this question's responses, with one respondent providing that they "would like to see regular education begin to own all students." Extending this concept, some responses indicated a desire for additional support focusing not only on inclusion, but also on the student's life outside of and after public education:

I wish that developmental services would provide robust services to meet family

needs in the community. I wish that developmental service providers could bill parent's insurance for these services. I wish these providers would partner with schools to wrap students in services.

This sentiment was also echoed in responses identifying that they wish to see "a fuller range of supports for students leaving the public school system that are accessible, available and easy to access for our students who have continued needs," as well as "more collaboration across agencies and funding sources to create continuity across settings for students and families."

Thematic Analysis of Findings

Through the analysis and examination of the data presented in this section, I have identified three major themes as emerging through the responses of the participants: a gap between education, experience, literature, and practice; the role that data plays in regards to intervention and treatment design; and the role that professional development, staffing, and available resources play in supporting or hindering treatment and treatment design, including the role that individuals' attitudes towards inclusion of students with ASD in their educational context. In the following subsections I will provide an analysis of these themes, with further discussion following in the subsequent chapter.

Gap between education, experience, literature, and practice. Earlier in this section I identified that the majority of participants reported both experience and training in their service of students with ASD, with 63.16% reporting seven or more years experience and 68.42% reporting graduate level coursework specific to ASD. I have observed that these relatively high rates of reported experience and study occur in parallel

to low rates of reported utilization of interventions carrying strong support by research literature. In some cases it was observed that interventions carrying low degrees of support in research literature were also reported as receiving high degrees of utilization. For example, 26.32% of participants reported never utilizing Theory of Mind related work, a conceptual framework central to much of the research literature and models of intervention with ASD. Additionally, 63.16% of participants reported varying degrees of use of Facilitated Communication within their districts, an intervention that has not demonstrated persuasive evidence outside of research that fails to utilize control procedures (Mostert, 2001), and whose prominence has been regarded as a product of anti-scientific sales tactics: An intervention that produces outcomes that are actually the product of those assisting the user (Jacobson, Mulick, & Schwartz, 1995).

In order to provide an analysis of reported practices in comparison to the degrees of support found in literature for these practices, I have provided Table 18, which builds upon data from survey Question 6, which asked participants to identify any interventions provided to students with ASD in their district. These responses were rated for frequency, and then collated into categories defined in a meta-analysis by the National Autism Center (2009) for corresponding levels of supporting evidence. Referring to the National Autism Center's (2009) standards report, established treatments are defined as: "Sufficient evidence is available to confidently determine that a treatment produces beneficial treatment effects for individuals on the autism spectrum" (p.32). Emerging treatments are defined as: "Although one or more studies suggest that a treatment produces beneficial treatment effects for individuals with ASD, additional high quality

studies must consistently show this outcome before we can draw firm conclusions about treatment effectiveness" (National Autism Center, 2009, p.32). Unestablished treatments are defined as: "There is little or no evidence to allow us to draw firm conclusions about treatment effectiveness with individuals with ASD. Additional research may show the treatment to be effective, ineffective, or harmful" (National Autism Center, 2009, p.32).

Table 18

Responses to Question 6 Collated Into Categories Defined by the NAC Standards Report

Intervention	Never	Seldom	Occasionally	Regularly	No Response
Unestablished Treatments					
Academic Interventions	0.0%	0.0%	5.26%	94.74%	0.0%
Auditory Integration Training	31.58%	31.58%	21.05%	10.53%	5.26%
Facilitated Communication	36.84%	21.05%	31.58%	10.53%	0.0%
Sensory Integration	0.0%	0.0%	26.32%	73.68%	5.26%
Emerging Treatments					
AAC Devices	0.0%	10.53%	26.32%	63.16%	0.0%
Cognitive Behavioral Intervention	0.0%	10.53%	47.37%	42.11%	0.0%
Developmental Relationship-Based Treatment	21.05%	21.05%	15.79%	21.05%	21.05%
Imitation-Based Interaction	15.79%	21.05%	26.32%	31.58%	5.26%
Language Training (production and/or understanding)	0.0%	5.26%	5.26%	89.47%	0.0%
Massage/Touch Therapy	63.16%	31.58%	0.0%	0.0%	5.26%

Music Therapy	63.16%	31.58%	0.0%	0.0%	5.26%
Peer-Mediated Instructional Arrangement	47.37%	36.84%	10.53%	0.0%	5.26%
PECS	0.0%	5.26%	21.05%	68.42%	0.0%
Scripting	10.53%	10.53%	31.58%	47.37%	0.0%
Social Skills Training	0.0%	5.26%	10.53%	84.21%	0.0%
Theory of Mind Training	26.32%	15.79%	36.84%	21.05%	0.0%
Established Treatments with Favorable Outcomes Reported					
Applied Behavior Analysis	5.26%	5.26%	36.84%	52.63%	0.0%
Other Behavioral Intervention(s)	0.0%	15.79%	21.05%	42.11%	21.05%
Joint Attention Intervention	26.32%	26.32%	31.58%	5.26%	10.53%
Modeling	0.0%	10.53%	15.79%	73.68%	0.0%
Naturalistic Teaching Strategies	42.11%	15.79%	5.26%	21.05%	15.79%
Peer Training	31.58%	31.58%	36.84%	0.0%	0.0%
Pivotal Response Treatment	42.11%	31.58%	5.26%	5.26%	15.79%
Schedules (textual or pictorial)	5.26%	0.0%	0.0%	94.74%	0.0%
Story-Based Intervention (e.g. – Social Stories™)	5.26%	5.26%	5.26%	84.21%	0.0%
Self-Management	5.26%	10.53%	15.79%	68.42%	0.0%

Of the four interventions identified as unestablished treatments, all four are identified as having some degree of utilization by participants. Academic interventions present a challenging piece of data, as without an operational definition, and given the

inherent nature of academic intervention indelible to the educational context, this type of intervention may be misidentified for the purpose of this study. For example, any student who receives "traditional teaching methods to improve academic performance" (National Autism Center, 2009, p.71) would likely be identified as receiving academic instruction in this survey regardless of whether or not it is indicated for their individual needs. Moreover, Vermont's laws clearly state that all students eligible for special education must be in need of "specialized instruction," suggesting that all would have academic goals on their IEPs. Discounting academic intervention for potential ambiguity and misunderstanding by participants, three other unestablished interventions remain. Auditory integration training and facilitated communication are reportedly being utilized in 63.16% of participants' districts, and sensory integration is reportedly used regularly in 73.68% of districts. These interventions are identified as having "little or no evidence" allowing "us to draw firm conclusions about treatment effectiveness" (National Autism Center, 2009, p.32).

Of the 12 interventions identified as emerging treatments, a varied mixture of utilization and lack of utilization is reported by participants. Five out of these 12 interventions are identified as being present to some degree within all participants' districts, and with the remaining seven interventions reported as receiving some degree of use, with AAC devices, language training, PECS, and social skills training all being utilized regularly by greater than 60% of districts.

Amongst established treatments with favorable outcomes reported, participants reported regular use of ABA, modeling, schedules, story-based intervention, and self-

management in greater than 50% of districts, with relatively high degrees of utilization within any frequency reported throughout all 10 established treatments. Exceptions to this include joint attention intervention, naturalistic teaching strategies, peer training, and pivotal response treatment, which are absent from some districts.

Role of data in intervention and treatment design. Mention and identification of the use of data appeared in many of the responses analyzed, with varying degrees of utilization of data as serving a role in the development, implementation, and monitoring of treatment and program design. For example, ABA inherently requires the use of extensive data methods as it views students as single subject research participants in a scientifically driven method of modifying behavior. 52.63% of respondents reported regular use of ABA, and 36.84% reported occasional use. Delving further into this area, individualized data was identified in 20 instances in response to Question 1, which asked participants to describe what, if any, methods of data collection and analysis are employed as part of direct instructional interventions.

In my review of participants' responses to all questions posed by the survey, I found that answers indicating use of data were quite limited in that simple mentions of data were provided, however, depth in response or further information pertaining to data use is limited. I believe that this may support the interpretation of these responses as being indicative of at least two potential explanations: A potential area of disconnect between participants, directors of special education, and the staff in their respective districts who perform the direct work of treatment design and implementation, resulting in a lack of awareness by directors of how data is collected, or a reflection of the limited

utilization of data driven processes in the treatment of students with an ASD.

Professional development, staffing, and available resources. Participants in this study provided feedback regarding their experiences and needs around professional development, staffing, and available resources for the service of students with ASD. In some cases, the lack of these variables was identified as a challenge. In other cases the availability of quality professionals, training, and related resources were heralded as cornerstones for the district's ability to serve students with ASD. Question 7 asked participants about what aspects of their district's current practices would be described as strengths in the development, implementation, and evaluation of instruction and intervention for students with ASD. Professional development and staffing both tied for the most reported answers, with eight instances each, followed by external consultation with six. Respondents identified that supportive administrators contributed to their district's strength, as well as team based screening and evaluation. One respondent identified experience and knowledge from multiple sources as contributing to their perceived strength: "Utilizing the experience of our staff and private providers knowledge of autism and programming. Info from UVM and the AOE on autism updates, literature, research and best practice. Instruction that is based on scientifically evidence based practices."

In contrast to responses identifying staffing and professional development as strengths, responses to Question 8, which asked participants to identify what challenges they perceive in regards to their district's current practices regarding students with ASDs, training was identified as the prevalent theme with 10 occurrences. Time, families, and

funding followed with five occurrences each. Some respondents stated that the individualized nature of ASD programming presents challenges, as it requires trained personnel and time to meet the students' needs. Within this question, the topic of attitudes held by regular education teachers also emerged, which will be discussed later in this document.

Challenges pertaining to staffing appeared to frequently include the time and funding necessary for the positions, as shared by one respondent:

> The need to have more staff trained, especially paraprofessionals. Funding! We cannot afford to lose the support required to keep staff trained, have the necessary technological resources, and to continue with our site-based program (which includes the mental health collaborative model).

Challenges regarding staffing and funding extended into areas pertaining to out of school supports, with one respondent identifying that "families need supports outside of school. They need BCBA consultation and trained staff to assist their children at home, in the community. Especially over school breaks." Another respondent wrote:

> Being able to provide services/resources for the high number of students who are being evaluated and discovered at an early age and sustaining services and staff with experience over time as students move along through the grades. Students being serviced as they begin to approach exiting from the public school system. Coordinating and collaborating with other potential agencies that may or may not provide services for older students regarding living arrangements, employment, continuing their education and use of the community.

One respondent identified limitations experienced as a result of limited time and money, and stated that they were in the process of "trying to home-grow a licensed BCBA to be a supervisory-union employee," which presents a potentially cost-effective strategy, however, also carries the concern that there "is no assurance that the employee will maintain long-term employment with us." The availability and ability to hire qualified professionals, as well as frustration with state level oversight was also voiced:

> I continue to search to hire more behaviorists with ABA certification/ license. It is tough to find qualified professionals. As for decision making I wish the state would survey SU's to see what innovative practices are happening around the state. It is disheartening to know children continue to be placed in ASD programs with limited access to peers and curriculum because they exhibit ASD behaviors or social interactions. I wish the state would also review the quality of some of the external consultants who rely on punitive practices (seclusion and restraint) as the basis of their ABA programs. I am always amazed there is not a review structure for these services for children and adults on the autism spectrum within the state. Some private ABA consultants cause great conflict between families and school districts.

The call for more training and development, and the support needed to achieve this, was echoed throughout many responses. In one example, this call included aspects of programming that could benefit more than students with ASD:

> Continued training and support in how to design effective programs relating to high quality curriculum, behavioral support and communication. I would like to

see increased independence, self-regulation and meaningful outcomes based on the long-term goals for the student. Sometimes, the day-to-day environment in a school building is difficult for students to sustain. I would like to see more Universal design of school days, technology, classrooms and buildings to assist in integrating students in a meaningful way. Training for teachers in regular ed to help design lessons, classrooms and schedules with students with autism in mind in order to include them and teach them with intentionality and make it meaningful.

In my work with this data I observed that many of the participants recognize a need for more assistance and involvement, not only in terms of funding or staffing, but also in terms of specific involvement of outside agencies and providers. The need for "consultation services available for helping with training of our staff – and of our teams," for "more collaboration across agencies and funding sources," and the openness to acknowledge that "we are eager to have more interagency plans for our students with ASD - and are heading in that direction with a couple of our younger students. By building a community of support/services as early as possible, we hope to decrease stressors for the family and student and increase resources that will be available 24/7," were all identified as salient examples of this call for help by some of this study's respondents.

The following subsection will discuss an issue specific to training and professional development that emerged through the same line of inquiry: The attitudes and understanding general educators hold towards students with ASD.

Inclusion of and attitudes towards students with ASD. The work of supporting students with ASD in educational contexts is often wrought with philosophical challenges. The imperative to educate students in the least restrictive environment often contrasts with the need for individualized treatment and presenting behaviors that at times, prohibit the ability to serve the student in a general education context. In Question 9, which asked participants to identify what they would wish to see happen for their district in regards to specific services/interventions and the decision-making process around service/intervention development for students with an ASD, three participants identified that they wished to see improvements around staff members' attitudes towards students with an ASD. Other responses touched upon this theme more tangentially, such as three additional responses indicating a desire for collaboration between service providers and school, eight instances of wishing for additional professional development and training, two for an ASD specific program, and five instances of wishing for trained individuals to provide support for teachers. In Question 8, which asked participants to identify what challenges they perceive in regards to their district's current practices regarding students with an ASD, two identified "exclusionary attitude(s) towards students with an ASD," as well, with 13 other tangential responses to this theme also appearing in regards to professional development/training for staff.

Some respondents identified that "case managers do not have the specialized training to implement the most beneficial programs," or, "significant lack of training in both regular ed and special ed teachers. Some of that is based on not having the perspective that these are everyone's students." Others identified more specifically that

challenge exists in the “attitudes of the regular education teachers who do not see them as part of their class and therefore do not invest in the student’s learning.” Another respondent identified that they “would like to see regular education begin to own all students.”

Chapter 5: Discussion, Conclusions, and Implications

Through this study I wished to gain knowledge and understanding of the services and interventions provided for youth experiencing an ASD in public school in Vermont. In support of this, I asked the following research questions:

- What services/interventions are provided for children/adolescents with an ASD in school districts, in Vermont?
- How are these services/interventions implemented for children/adolescents with an ASD within school districts in Vermont?
- Why are these services/interventions applied to students with an ASD in school districts in Vermont?

The participants in this study answered a survey detailed throughout the preceding section of this document, providing information about their own professional development and awareness of topics pertaining to ASD services, as well as their district's practices. In this final chapter, I discuss the findings of this study, the limitations of the study, implications for future practice in a local context, and implications for future research.

Summary of Findings

The following subsections reiterate the themes identified in the previous chapter: The gap between professional experience/training and the implemented practices; the role of data in intervention and treatment design; and finally, the role that professional development, staffing, and available resources play in a district's ability to serve students with an ASD, including the role that attitudes can play in this context. In order to address

my three research questions in an organized and meaningful manner, I have chosen to discuss each of these themes as separate entities, with the three research questions applied through the discussion of each theme.

Gap between education, experience, literature, and practice. In Chapter 4 I presented data indicating that participants of this study report having fairly significant amounts of experience serving students with ASD, with the overwhelming majority reporting more than four years of experience in this area. Also, the majority of participants report having moderate to significant levels of training in regards to interventions for students with an ASD. These reports seem to contrast with the data reflecting utilization of unestablished treatments in some districts, as well as a lack of utilization of established or emerging treatments. The reported high rates of experience and education, coupled with a lack of utilization of interventions supported by clinical literature, as well as the use of interventions lacking support in clinical literature, present a disconnect between the two sides of clinical practice: the evidence base supporting practice, and actual practices implemented. This gap between education, experience, practice, and the literature regarding ASD treatment/services is a point of particular interest to me, as it presents an area whereby school systems and mental health providers can work together to help narrow the distance between these variables.

The use of unestablished treatments is not uncommon to the field of ASD treatment (American Academy of Pediatrics, 2001; Mayton et al., 2010; Parsons et al., 2013). I did not expect to find that unestablished treatments were being utilized on the scale found in this study, however. My assumption was that higher rates of reported

education and experience in this specific field would be correlated with high rates of utilization of established and/or emerging treatments, and low rates of utilization of unestablished treatments. The utilization of established and emerging treatments far outweighs the use of unestablished treatments; however, the presence of use of unestablished treatment raises the question of why these unestablished treatments continue to be utilized, and why higher rates of established or emerging treatments are not observed. In consideration of the concerns voiced by participants regarding availability of financial resources and staffing, I wonder why available resources are being utilized to implement interventions that are identified as having little to no evidence supporting them. When considering the range of practices utilized in support of individuals with ASD in Vermont, on a national level it is also found that unestablished, practices are utilized (National Autism Center, 2009). In one example, a respondent identified that their district's strength was in "a healthy balance of Skinner's ABA and Maslow's Hierarchy," a response that revealed a lack of understanding or knowledge regarding clinical interventions. B.F. Skinner did his work in behaviorism some 30 years prior to the emergence of ABA, and Maslow's hierarchy of needs is not a clinical intervention, but rather, a theoretical framework. Examples such as this brought questions pertaining to epistemology to the forefront.

In addition to these examples of potential disconnection between experience and interventions utilized, I also perceived other areas of potential disconnect, such as in regards to assessment and the development of treatment programming. The most frequently identified codes pertained to ASD-specific and supplemental assessment;

however, responses indicating that no ASD-specific assessment tools were being utilized present a reason to pause and consider the impact of such practices. Participants also identified School Psychologists and Special Educators as the professionals most often responsible for conducting assessment, including some responses that stated explicitly that the district had hired doctoral level psychologists with training specific to ASD. A School Psychologist and/or Special Educator may be the most readily accessible individual with training pertaining to ASD; however, it is not clear to what degree specific training in ASD is typically included in professional preparation programs, and work specific to ASD in many cases may lie outside that individual's professional training and experience. In Question 5 I observed a similar pattern, in that some respondents indicated that they deferred to contracted agencies for the qualifications necessary to fulfill the role of consultant on their teams, while others were able to explicitly identify qualifications such as holding a BCBA. Some responses included statements that indicated a lack of awareness/knowledge by painting broad strokes utilizing common, but unspecific terminology such as "license," without specifying what license a contracted service provider holds. Currently, there are no ASD specific licenses available in Vermont; there are significant efforts to provide licensure for BCBAs underway, but this plan has yet to reach fruition.

This theme provides information that speaks to the research question asking what services/interventions are provided for children/adolescents with an ASD in Vermont. The regular use of unestablished treatments such as facilitated communication and sensory integration present questions pertinent to this study in the simple question of

why they are being utilized. My third research question asks just that: Why are certain services/interventions applied to students with an ASD in school districts in Vermont? While my survey did not ask questions pertaining to clinical reasoning and/or decision making in a direct fashion, questions such as those pertaining to data collection, assessment tools, qualifications/positions held by those conducting assessments, the role of external consultation/service provision, how programs are designed, as well as the strengths/challenges perceived within a district, all may lend further insight into the question of why these services/interventions are applied.

Role of data in intervention and treatment design. Earlier in this dissertation I noted that ABA is often cited as the intervention with the strongest empirical evidence in treating students with ASD (Rosenwasser & Axelrod, 2001, p.671). This position in the realm of treatments and methodologies is in part a result of ABA's use of scientific and systematic principles to provide data driven processes to treatment. It therefore effectively increases the ability of clinicians and practitioners to rely on objective data rather than anecdotal reports in their monitoring of progress as well as in the development of programming.

It was not surprising to me to find significant mention of data as serving a role in the development of treatment, implementation/monitoring of treatment, and program design in the responses collected from this study's participants. Approximately half of respondents reported regular use of ABA, with roughly a third reporting occasional use. Delving further into this area, the majority of participants reported that individual level data is utilized in the process of data collection and analysis. The frequency of these

responses present potential indicators that individualized treatment is well understood as a primary area of importance in ASD treatment; however, the limited number of responses identifying specific areas of data utilization leaves questions regarding the quality of this data. Without further detail, data may be comprehensive, or it may be anecdotal or otherwise inadequate for the purpose of treatment.

Data regarding participants' awareness and understanding of the role that objective data plays in treatment also emerged through more general, open-ended questions. In one example a participant stated, "I have some wonderful pools of talent, we are not very scientific in our approach. However, I think the students are meeting with success." This response raised questions for me about both professional development of direct care staff, as well as overarching understanding of the role of scientific process vs. anecdotal data. This respondent presented a balanced anecdotal appreciation of their situation, however, she/he also identified a lack of scientific approach and a reliance upon individual perception rather than objective data.

In considering data and its role in treatment design and programming, I found myself considering the role that professional development plays across the landscape of professionals involved in any one student's treatment and education. In many examples, it appeared that participants held some degree of understanding of the role of individualized programming, and likewise, data use in regards to treatment. In some examples, many of which were common to the previous case, a deeper, substantive understanding of what constitutes data and how the scientific process is intended to be utilized in regards to data and outcome reporting, was absent. Overall, my examination

of research Question 3 led me to conclude that current practices around data use are inconsistent and may warrant future inquiry. What role does the professional development of play on the implementation of treatment design and utilization of practices?

Professional development, staffing, and available resources. Within any given district and perhaps more than any other variable, the training, knowledge, experience, and availability of staff members are critical to ensuring effective use of interventions and positive student outcomes. Having solid leadership and clinical support from a director of special education may be an invaluable asset for a district, and may determine much in regards to treatment and collaboration with other providers. Additionally, the degree to which the staff who provide treatment design and direct service are directly connected to each individual case and can make or break an experience for a student with ASD and their family. Given the relatively high degree of visibility that professional development, staffing, and resources have within a school and its community, it was not surprising to me that this study's participants were highly engaged with this topic.

Responses provided in regards to professional development identified elements such as the important, positive role that supportive administrators play in a respondent's perception of their district's strength. Additionally, information from UVM, the AOE, and outside service providers was identified as strength as this information supported "instruction that is based on scientifically evidence based practices." In contrast to these areas of strength, the need for training was reported as the prevalent area in need for

support, with some participants indicating that the individualized nature of ASD programming presents its own challenges in regards to resources and training.

Participants' reporting of the need for time and funding necessary for the positions associated with ASD treatment was prevalent and clear. These responses provided detailed information regarding the perceived need for additional support in the work with families outside of school, the need for more BCBA consultation, the need for transitional support for students leaving school, and the need for more trained staff both in regards to direct service and treatment design, were all prevalent in the data.

Closely related to these identified areas of challenge, was a theme pertaining to the attitudes of staff towards students with an ASD. As described in Chapter 4, some respondents identified a lack of training for case managers, regular education, and special education teachers regarding ASD specific treatment and programming. These responses also suggested that there exists significant challenge in that some educators adopt the perspective that students with ASD are not their responsibility, and therefore they don't invest in the students' learning. These reports are not surprising to me, as in my professional experience I have often observed situations in which this was the case.

School systems are known for the financial challenges they face each year. Resources are inherently limited, and treatment/education programs for even one student with an ASD can cost significant time and money. These unique needs present a challenge for school districts, particularly those that lack the size and affected population size to support exploring dedicated treatment programming, hiring dedicated staff for ASD services, or other cost-saving measures that can ultimately make service provision

more effective and efficient.

Summary. The earliest preferred treatments for ASD were psychoanalysis and nondirective play therapy, which were applied in response to the belief that ASD represented an emotional reaction to environmental factors (Heflin & Simpson, 1998a). From where we stand today, it is easily perceived that these early efforts were not effective for a variety of reasons. We have come to learn that most interventions based on the formation of interpersonal relationships lack support from research outside of testimonials and anecdotal report (Heflin & Simpson, 1998a; Simpson, 2005). Seventy-two years have passed since ASD was first discovered, and yet, controversy still exists regarding treatments for ASD. While an exceptional amount of research has been amassed during this time, it is still clear that much of this research continues to be underutilized on a national level, as well as here in Vermont. I will explore this underutilization of research as it pertains to the research-to-practice gap, and the role that epistemology plays in this dynamic, later in this chapter.

Limitations and Comments

The trustworthiness and validity of any research is of utmost importance; Creswell (1998) identified that to answer the question of how we are able to know that a qualitative study is valid, we in turn must introduce standards of quality and our approaches to verification (p.193). Initially, I had anticipated that the descriptive nature of this study would avoid many of the challenges common to qualitative research, as I thought that there would be little interpretation involved in the gathering and analysis of answers to the question: What services are provided for students with an ASD? Similarly

I thought that limited interpretation would be involved in the gathering and analysis of answers to the question: How are services provided for students with an ASD? I had also thought that substantially more interpretation would be employed in the analysis of questions pertaining to *why* specific services/interventions are applied for specific students. However, I came to find that this research question was not explored as I had intended.

As is often the case when one imagines a large project ahead of them, particularly a project that is atypical of much of their previous work, my initial thoughts on the scope of interpretation in the analysis of this study's survey data were reflective of my relative inexperience. Having previously authored an individual case study in the context of a clinical psychology program, I was accustomed to much more interpretive and in-depth analysis of individual case data, as is typical for work in the Freudian case-study tradition. This experience revealed that such depth and interpretation would not be appropriate or feasible, which lead me to expand my perspective and how I understand the analysis process.

I also came to find that participants' responses to the questions presented to them often raised more questions than answers. I found that many answers suggested much larger issues at hand than I had initially perceived, such as responses in which "Skinner's ABA" and Maslow's Hierarchy of Needs were provided as strengths in practice, when in actuality, these answers revealed a potential disconnect between education, training, and implementation. I found that seemingly clear-cut answers provided significant room for analysis, questioning, and the opening of even further

questions to delve deeper into the participants' knowledge and experience. I choose to identify this as a limitation, as it initially appeared to be a limitation in consideration of the narrow function of my research questions. When taken into consideration of the broader purpose of this study, I believe the unfolding of this observation has proven to be an area of strength.

The scope of this research is limited to the state of Vermont, or more specifically, to the participants of this study within the state of Vermont. This presents the most obvious limitations for this study's capacity for generalization. I requested data from each of Vermont's 58 directors of special education and those with equivalent title, and I received 27 responses. Of these 27 responses, 19 were complete and were considered for the study: approximately a third. While some would consider this a relatively strong sample, it nonetheless hinders the generalizability of the study's findings from being reflective of the practices and processes underway state-wide. The inclusion of only directors of special education and those with equivalent title omitted the perspectives of others involved in the decision-making processes, such as parents, the students themselves, Special Education Case Managers, Behavior Interventionists, and others. Additionally, I was aware that the directors of special education and those with equivalent title within any given supervisory union may or may not have as clear of an understanding of the details involved in service delivery and implementation. However, the expressed knowledge or lack thereof of these details provided important information in another perspective, that is, administrators' awareness of practices for students with an ASD within their own supervisory union. It is perhaps this point that the study grew to

explore, more than its direct line of questioning: the actual awareness and connectedness that those surveyed have with their district's practices, and with the knowledge base surrounding ASD treatment.

If I were to reattempt this study, I would have chosen a far broader scope in my sample population. Surveying parents, Behavior Interventionists/Paraprofessionals, Special Education Case Managers, and others involved in serving students with ASD would have provided a more diverse range of perspective. Additionally, moving beyond survey data as the lone means of data collection, including methods such as interviewing and direct observation would provide greater depth of information, as well as providing a means to conduct a more extensive analysis of how services are implemented in vivo.

I also came to realize that this study did not ask questions regarding the range of symptoms experienced by the students served by each district. This detail could provide additional clarity regarding how and why certain interventions are applied at their respective rates, as well as regarding the service needs experienced by a district. This is an area that made sense to omit from this study, however, could provide interesting perspectives and information in future research.

Implications for Future Practice in Local Context

The analysis and discussion of the results of this study uncovered three prevailing themes: the gap between education, experience, literature, and practice; the role of data in intervention and treatment design; and the role that professional development, staffing, and available resources have on districts' ability to serve students with an ASD. The prevalent responses citing a lack of time and financial resources were

somewhat predictable, as this is a theme often observed across public education regardless of specific area of focus. For the sake of this study, it was important to identify this; however, I do not seek to address this issue here due to issues of scope and context. Instead, there was a topic that I observed to emerge across all three of these identified themes: epistemology.

Shtulman and Valcarcel (2012) examined the role that scientific knowledge plays in the context of previous knowledge or intuition, and suggested that "when students learn scientific theories that conflicts with earlier, naïve theories…naïve theories are suppressed by scientific theories but not supplanted by them" (p.213). Some see this notion as central to the ongoing debate regarding vaccination and the purported link between vaccines and ASD, and as an explanation for why scientific evidence is often unable to convince or be considered by those who hold naïve theories as truth. Scott-Phillips (2015) claimed that "Naïve theories of all kinds tend to persist even in the face of contradictory arguments and evidence. Interestingly, they persist even in the minds of those who, at a more reflexive level of understanding, know them to be false" (Naïve Theories section, para. 4). Scott-Phillips explained that this phenomenon occurs because our primary way of seeing the world is through an intuitive, naïve level of understanding, with science education coming in second in our perceptual influence.

I bring these references to light because they relate to themes that recurred throughout the study: the role that epistemology plays in decision-making, specifically in regards to treatment design, and a person's awareness of their own biases, education/training, and other aspects of their individual perception versus more objective

data. In one way or another, many responses in this study touched upon the topic of epistemology. One participant noted that he or she perceives conflict between families and schools as emerging at times due to outdated information presented to families by the state of Vermont, medical practitioners, and the Vermont Family Network. This may result from dynamics involving a disproportionate emphasis on information delivered from these sources, despite contrasts that may exist between the source and more current literature. The overwhelming majority of participants self-identified as having substantial amounts of experience and training in regards to interventions for students with ASD. And yet, despite these high levels of reported experience and training, significant gaps between knowledge and practice were observed, such as the response that indicated that the participant's district has talented staff who are "are not very scientific" in their approach, but that nonetheless, "the students are meeting with success." These responses raised the questions of how the participant actually knows that his or her students are successful in their treatment/education, as without a data driven process of evaluation, this could presumably be left to anecdotal observation—and as such, prone to significant bias.

Beyond the salient issues of time, money, and related resources, I came to perceive that these foundational issues pertaining to knowledge and how we come to accept, revise, and work with knowledge, were central to the emergent themes of education, experience, practice, professional development, attitudes, etc. Beneath each of these themes lies questions about how and why specific knowledge is given an active stage in the development of a plan to provide a student education. How does one come to

accept the implementation of interventions found to be unestablished, or in rare cases, detrimental? How does one come to understand the role that data collection plays beyond a cursory overview and rather as an integral component of scientific process? How do we support adult professionals in their ability to utilize scientific principles such as evidence vs. anecdote in their assessment of programming? In the local context, my hope is that this study and others like it can help support and inform educators and administrators regarding the lack of connection that may occur between literature and practice, and all that lies between. This study strongly affirms the existence of the gap between research and practice that has been identified by other researchers (Abbott, Walton, Tapia, & Greenwood, 1999; Dingfelder & Mandell, 2011), however, it also raises questions regarding the role of epistemology in the clinical work associated with ASDs.

In my professional work I tend to place a relative degree of primacy towards objective, or perhaps more accurately, semi-objective data. This is at times a deliberate bias of mine, which is contrasted by my training in psychodynamic aspects of clinical psychology and work in the field of public mental health. I tend to lean towards objective data because much of my field is influenced greatly by subjective data: I employ objectivity as a counterbalance to the subjective nature of clinical psychology. Because of this dynamic, my perspectives on ASD treatment tend to lend primacy to the role of formal research and science. These perspectives on ASD treatment have been influenced by experiences where I observed subjective data to present detriment or roadblocks to a client's treatment and success. This isn't to suggest that formal research

and science have inborn primacy in regards to ASD treatment, rather, that the dance of integrating multiple sources of knowledge in the process of providing treatment for individuals with an ASD, can at times be complicated.

Previous research has identified issues with the traditional model of professional development in public schools, such as the top-down educational research model, a lack of input from teachers and others implementing interventions, and challenges in linking research to professional development, all of which contribute to the research-to-practice gap (Abbott et al., 1999). The dissemination of information is an inherent challenge in the public school context, particularly given that professional development is often limited to relatively brief trainings, and teachers and staff are expected to implement new practices based on these trainings. The diffusion of innovation model may hold some value in this area, as it considers social context as being the primary variable in the reception of new information (Dingfelder & Mandell, 2011). I suspect that the social dynamics at play within a the milieu of a school's professional staff, as well as the macro-milieu present within a district, state, or region, plays a powerful role in determining the responses that individuals produce when presented with new information and how they respond to new information and expectations for practice.

Despite being the most common approach, passive dissemination of information is not effective, and at best only produces small changes in practice (Bero et al., 1998). Some researchers have suggested that dissemination and implementation of information be rigorously evaluated (Bero et al., 1998), a suggestion that I support, if only to provide reliable data rather than anecdotal observation. In reviewing some of the identified

reasons for the research-to-practice gap, I perceive that elements such as separateness of the research and practice communities, issues of relevance, usability of research based innovation, and lack of communication between members of each community (Greenwood & Abbott, 2001) are indicative of a social disconnect, as well as a product of the convergence of disparate perspectives. In light of this, we can see how policy efforts such as those requiring educators to support their interventions with research may not result in salient change. If the educator is not a member of the research community, she or he may experience some degree of ambiguity or even discord when asked to support their practices with knowledge from what is, essentially, a different culture.

In order to help bridge the gap between research and practice, the gap between the cultures and professional habitus of researchers and educators must be bridged. In my personal experience in an ABA driven program that operated within a public school environment, I often observed a gap between BCBAs, who are trained to rely heavily upon scientific methodology, and educators, whose day to day practice is often removed from scientific methodology. This gap was difficult to bridge, often because both parties employed different epistemological structures. An appreciation of the value of another person's perspective is often dependent upon our ability to understand the origin of the other's perspective, instead of seeing it as simply contrary to our own.

In looking at the gap between research and practice, and more specifically, the cultural component of this gap, I find myself referring to aspects of clinical practice that work with these concepts. A cultural gap that I am accustomed to bridging is one between families and service providers such as school systems, mental health providers,

state agencies, etc. There is often an inherent gap in the culture of a family system and the culture of the professionals serving that family system; at times, it is as visible as the differences in clothing, or as audible as the differences in language. In direct clinical work, this gap can be bridged by employing a number of therapeutic techniques, all of which tend to focus on building a relationship between those at either side of the gap. Through focusing on the relational aspects of the work, people on both sides of the gap tend to develop mutual respect and appreciation for each other's knowledge and experiences. Perhaps this is an area of potential growth for the field: looking towards ways that the cultures of those in the practice and research communities can be bridged through dialogue, participation, and exposure to each other's' respective experiences.

Implications for Future Research and Final Thoughts

At times the process of conducting this study raised an overwhelming array of questions, the result of my desire to cover as much territory as possible. As I progressed and accepted that I would not be able to realistically cover all of these emerging areas of interest, I came to develop the following questions and areas of potential future research.

In looking at my second research question, how services/interventions are implemented for students with an ASD within school districts in Vermont, I recognized that this study did not adequately address this question. In hindsight, I recognize that my survey did not elicit responses that directly addressed this issue, and in some ways this question could have been a study in and of itself. Regarding my first and third research questions, what services/interventions are provided, and why these services are applied, I

feel that my study yielded some important results. While the survey could have been better formulated to directly address the question of *why* specific services/interventions are applied, the responses that emerged were nonetheless thought-provoking. It is in the answers to these two research questions that I found the greatest clarity in regards to areas for potential future research, as well as the most important insights that I will carry away from this experience.

As I discussed in the preceding section, epistemology plays an important role in issues pertaining to professional development, attitudes, and clinical decision making. Further research into this subject could offer a substantial contribution to our understanding of public school systems and ASD. Issues pertaining to professional development are central to all aspects of ASD treatment in public schools across a wide range of professional involvement: from the paraeducator who spends his or her day working with a student, to the administration who supports special education practices on a whole. Moreover, issues of professional development and the epistemological considerations held therein are also applicable and meaningful in a school's work with families who request support in their parenting of a child with ASD. The mechanics of how we come to understand the information we receive, how we come to make observations, what information we accept vs. cast aside, our own self-reflection and utilization of scientific processes to separate anecdote from objective data, etc., all impact each and every step of the work involved in education. Perhaps more central to the issue of epistemology is the issue of cultural differences between the research community and those implementing and supporting the implementation of actual services. This is an area

that requires further inquiry and study, so as to help inform creating meaningful connections between those studying educational practices and those implementing them.

This study presents data demonstrating that there are a range of practices implemented in Vermont, with varying degrees of evidence based support. This is reflective of national patterns, and illustrates a need for further support in Vermont's policy, practice, and professional development of educators and administrators. That the research-to-practice gap exists is undeniable. The question that came to mind as I completed this study is *how* we can bridge the gap between research and practice spheres, as well the individuals and families served by researchers and educators. Current practice is almost like a game of telephone, beginning with researchers, crossing through administrators, educators, and practitioners, and ultimately reaching the individuals and families served. At times, this game of telephone achieves parity between the messages sent by researchers and those received by consumers, but at other times, the message becomes drastically distorted. My hope for the future of Vermont's schools and students is that we may be able to utilize, inform, and consume existing research to its fullest capacity, while also participating in the dialogue surrounding emerging research.

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Appendix A: Open Ended Survey Questions and Related Codes

Question 1: Please describe what, if any methods of data collection and analysis are employed as part of the direct instructional intervention(s) identified in the previous question:

Q1:BI – Behavior Interventionist taking data
Q1:IndiData – Individual, daily data
Q1:MonthlyReview – Monthly review of data
Q1:Nondescript – Answers that do not explicitly specify what methods of collection and/or analysis are employed
Q1:ProgressReports – Typical school-based progress reports, including IEP
Q1:TherapyNotes – Therapy notes
Q1:WeeklyReview – Weekly review of data

Question 2: What, if any, specific assessment tools are employed to guide the development of a student's program? (e.g. - diagnostic, developmental, adaptive, communication, intelligence, assessments such as the Autism Behavior Checklist, Psychoeducational Profile-Revised, Vineland Adaptive Behavior Scales, Reynell Developmental Language Scales, respectively)

Q2:AutSpecific – ASD specific assessment tool(s)
Q2:IDK – "I don't know"
Q2:NoAut – No ASD specific assessment tool(s)
Q2:NonDescript – Vague answer(s), not identifying a specific assessment tool
Q2:SUPP – Supplemental assessments such as those commonly provided by Occupational Therapists, Physical Therapists, Speech and Language Pathologists, and/or School Psychologists.

Question 3: What are the position(s) of individuals responsible for conducting assessments?

Q3:BCBA – Board Certified Behavior Analyst
Q3:CDC – Center for Disease Control and Prevention
Q3:MD – Physician/Psychiatrist
Q3:NonDescriptBehaviorSpecialist – Generally identified behavior specialist without identified qualification(s)
Q3:OT_PT_SLP – Occupational Therapist, Physical Therapist, and/or Speech and Language Pathologist
Q3:PARA – Paraprofessional
Q3:PSYCH – School Psychologist
Q3:SPED – Special Educator

Question 4: What role, if any, do external consultants (via public mental health or

private organizations) play in the development of a student's program?

Q4:Consult_and_Staffing – Consultation and Staffing
Q4:HeavyConsult – Heavy dependence on outside consultation
Q4:HomeSupport – Support for families at home
Q4:IndProgDev – Individual program development
Q4:MinimalConsult – Occasional and/or minimal utilization
Q4:ProfDev – Training for staff
Q4:SuppSvcs – Supplemental services such as Occupational Therapy, Physical Therapy, etc.

Question 5: If consultation (internal and/or external) is utilized, what certifications or related qualifications do the consultants carry (in reference to their roles, not specific individuals)?

Q5:AUT – "Autism Specialist"
Q5:BCBA – Board Certified Behavior Analyst
Q5:MD – Medical degree
Q5:NON – No certification/qualification, no answer, and/or an unofficial or unrecognized certification/qualification.
Q5:OT/PT – Occupational/Physical Therapist
Q5:PARA - Paraprofessional
Q5:PSYCH – School Psychologist
Q5:SLP – Speech/Language Pathologist
Q5:SPED – Special Educator

Question 6: How are programs for students with Autism Spectrum Disorders typically designed

Q6:AssessmentDriven – Assessments and/or data used to inform intervention
Q6:COLLAB – Collaboratively with the team, sans Family unless also coded with "Q6:FAMILY"
Q6:FAMILY – Working with the family
Q6:INDI – On an individual basis
Q6:NonSpecificAnswer – An answer that does not identify how programs are developed.

Question 7: What aspects of your district's current practices would you describe as strengths in the development, implementation, and evaluation of instruction and intervention for students with an Autism Spectrum Disorder?

Q7:Admin – Supportive Administrative structure/individuals (superintendant, etc.)
Q7:Collab - Collaboration
Q7:EarlyIntervention – Early intervention programs and support
Q7:EBP – Evidence based practice
Q7:EVAL – Evaluation and assessment

Q7:ExtConsult – Collaboration with external consultation
Q7:Inclusion – Focus towards inclusion and independence
Q7:IntConsult – Internal consultant
Q7:Meeting – Regular meetings by teams
Q7:Model – The model of treatment and intervention
Q7:ProfDev – Identifies that the district is learning, engaging in development
Q7:Staffing – Staffing
Q7:Tranisition – Support for individuals in transitional stages
Q7:Variety – Having a variety of interventions available

Question 8: What challenges do you perceive in regards to your district's current practices regarding students with Autism Spectrum Disorders?

Q8:Attitude – Exclusionary attitude(s) towards ASD students
Q8:Distance – Geographic distance and accessibility
Q8:Families – The need for more support for families
Q8:Funding – Lack of financial resources
Q8:Independence – The lack of independence demonstrated by a student
Q8:IndividualizedNature – Individualized nature of ASD services
Q8:Personnel_LackOf – Lack of enough trained personnel
Q8:SmallPopulation – Small number of students with an ASD
Q8:Sustain – Ability to sustain services from an early age through transition out of public school.
Q8:Tech – Ability to keep up with technology that can be used to support students.
Q8:Time – Time
Q8:Training – Training for staff
Q8:Transition – Issues pertaining to the transition of students out of public school into independent adulthood

Question 9: What would you wish to see happen for your district, in regards to the specific services/interventions and the decision-making process around service/intervention development for students with an Autism Spectrum Disorder?

Q9:Attitude – Improvements around staff's attitudes towards students with an ASD
Q9:Collab – Collaboration between service providers and school
Q9:Consultation – Additional consultation available
Q9:Data – Stronger data collection/tools
Q9:EBP – Implementation of evidence based practices
Q9:Eval/Assess – Evaluation and assessment leading to instructional direction
Q9:Funding – Availability/access to funding for services
Q9:Happy – Identifies that the respondent is content with current services
Q9:ProfDev – Additional professional development and training
Q9:Program – Would like to have a specific program for students with an ASD
Q9:Space – More physical space
Q9:StateOversight – Increased degrees of oversight from the Department of Education

Q9:TrainedStaff – Trained individuals to provide support/consultation for teachers and families
Q9:Transition – Support for students in transition out of public school into the community